

I KNOW YOU CAN'T SEE IT BUT IT HURTS

A Research Study into the Experiences of Young People, Their Parents and Healthcare Professionals, Who Live and Work with Medically Unexplained Physical Symptoms (MUPS).

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ABSTRACT

In this study I have explored first-person stories of young people, parents and healthcare professionals about their experiences of living and working with medically unexplained physical symptoms (MUPS). MUPS claims large amounts of healthcare professionals' time and technological resources in primary and secondary healthcare. As a consequence there has been an increasing amount of research interest in MUPS sufferers in recent years. However, few studies have explored the experience of MUPS sufferers from a social constructionist, dialogical and narrative epistemological standpoint.

A cross-disciplinary review of the literature on MUPS revealed the experiences of young people and their families to be similar to those with a diagnosis of chronic illness and their families. A dearth of qualitative studies have explored the first-person accounts of young people, their parents, and healthcare professionals who live and work with the condition. Research aims were generated following the review of the literature:

- To explore the meanings that young people, their parents and healthcare professionals attach to their experience of MUPS in the absence of a medical diagnosis
- To explore stories constructed from these experiences by young people, their parents, and healthcare professionals about the impact of MUPS upon identity and significant relationships
- To discover the discourses and narrative templates that inform healthcare professionals' practice with young people and their families who live with MUPS
- To identify cultural and institutional discourses and narrative templates from focus group members' stories of experience; that position or marginalise MUPS sufferers and their families.

The focus group method was chosen for data collection. Seven focus groups were held in a Paediatric Liaison Department (PLS) in a Regional Hospital in the East Midlands, U.K. Young people and parents were recruited to the focus groups from historical casework of the PLS Department. Healthcare professionals were recruited from the hospital paediatric and PLS teams. The focus groups involved two groups for adolescents with MUPS and two groups of parents of adolescents with MUPS. Three other focus groups involved healthcare professionals who work with adolescents and their families with MUPS.

The focus group discussions were videotaped and transcribed by the researcher and two forms of analysis were employed: Thematic Analysis (TA) and Dialogical Narrative Analysis (DNA).

The two forms of analysis produced multiple literal themes and implicit stories abstracted from focus group members' accounts. A major theme for young people and parents was their feelings of anger and frustration following the initial medical interview with their doctors. Young people and parents reported they were not only disbelieved by the doctor about the existence and severity of the symptoms, but the doctor attributed negative attributions about their presentation such as 'You're lazy', 'It's psychosomatic', 'All in your head', 'Fussy parent'. Without a diagnosis concerns of the young people and their parents were not legitimised. Young people and parents lost confidence in medical institutions. Young people responded by withdrawal and increasing social isolation. Many parents took on the role of advocacy in an attempt to restore their child's credibility and the family's integrity.

Some of the doctors interviewed spoke about the dearth of training in MUPS in both paediatrics and psychiatry. They suggest that managing MUPS patients can be very time-consuming for hard-pressed clinicians. Within the medical encounter they sometimes feel pressured or ambivalent about whether to continue to investigate despite previous negative results. Doctors also stated that MUPS patients can generate anxiety and uncertainty in clinicians.

More main themes emerged including recognising MUPS as primarily ‘an idiom of distress’ and the shortcomings of the biomedical paradigm in addressing the problems and dilemmas of MUPS sufferers, their parents and healthcare professionals.

In the Discussion Chapter I propose a model of training and CPD for healthcare professionals. The model proposes introducing a hermeneutic approach and open emotional postures to compliment the deductive role of the diagnosing physician. It is proposed that by accessing concepts from both the scientific and phenomenological paradigms healthcare professionals will reduce the possibility of incongruence and potential for impasse within the physician-patient relationship.

In the conclusion of the report a number of recommendations are given based upon the outcomes of the study to introduce the benefits for professionals in adding theoretical concepts from systemic family psychotherapy, dialogical and narrative theory to inform and promote a hermeneutic discursive centred practice with MUPS sufferers and their families.

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CHAPTER ONE

1. Introduction

I will begin this introduction by giving a brief description to illustrate the way in which a young person with MUPS may present at the point of referral to a CAMHS Paediatric Liaison Team in a regional hospital in the U.K:

Clare, aged 15, who was referred to the hospital paediatric liaison team by her consultant paediatrician, is unable to walk because she has “terrible pain” in the sole and ball of her foot, which has gradually spread to the rest of her leg. Clare first presented in orthopaedic outpatients at the age of seven. In the succeeding years extensive medical investigations proved to be inconclusive. Clare’s medical history included viral meningitis in the first year of her life; asthma and eczema; a pulmonary stenosis repaired at the age of nine, which if not treated could have been life threatening; and problems with her palate which required surgery.

Clare’s father’s first wife died from cancer, a leiomyosarcoma, which initially presented as a lump on her leg, but took some time to diagnose, by which time the disease had spread and become inoperable. Her father was left with five children to care for until he married Clare’s mother, a divorcee who brought four children to the relationship. Clare is the only child of their relationship, and lives solely with her parents, since all her half siblings have left home. Clare has been virtually housebound for a year, and, since she has not been able to attend school, has lost touch with most of her friends.

Clare and her parents have expressed anger and frustration about the failure to find a cure and stop the pain. They believe they have received conflicting messages from the doctors, and have never been given a clear reason for the cause of the pain. Clare’s memory is that the pain started one day when she was stepping into the bath.

The challenges and dilemmas faced by young people like Clare, her family, and healthcare professionals in this situation inspired my research interest in MUPS. The decision to embark upon a research thesis late in my career coalesced with joining a small Paediatric Liaison Service (PLS) within a large regional hospital to work with sick children and their families, in 2004.

The PLS team has a dual primary task: first, to offer direct psychotherapeutic work to children, young people and their families who are patients of the hospital paediatric services and second to provide supervision, consultation, and teaching to healthcare staff on psychotherapeutic issues relating to the care of children, adolescents and their families who experience acute, chronic and life threatening illness.

As a clinician with over 30 years of experience in social work and Child and Adolescent Mental Health (CAMHS), I embarked upon my new role with a nervous enthusiasm but with a resolution to remain open to new learning. I was determined to maintain an ethical and respectful stance with colleagues from different healthcare backgrounds, and to try to remain 'curious' about different worldviews and approaches.

I had a number of insecurities and self-doubts. Would a family psychotherapist with virtually no experience of physical health, influenced by social constructionist and narrative ideas find a fit in a biomedical world with its medical hierarchies and professional 'expert' positions? How would I position myself with the binary language of diagnosis and treatment protocols in the highly structured environments of wards and outpatient clinics?

I trained in Post Milan Systemic Therapy in the mid 1990s. During the training I was stirred by the influence of post-modernist theory in my life and clinical practice. In the post-qualifying work I somewhat idealistically vowed that I would no longer conceive of myself as an outside observer and would aim to be a self-reflexive participant in most, if not all, of my social and clinical encounters.

This commitment entailed a theoretical shift from modernist to post-modernist theory and practice. On reflection, the aims were rather idealistic, as often it was difficult to sustain a post-modern stance in the increasingly clinically managed world of generic CAMHS. However, I saw the new job in PLS with an often vulnerable and marginalised clinical population as an opportunity to re-engage more fully with a post-modern stance, which gives theoretical prominence to dialogical and narrative epistemology in the exploration of human experience.

In some respects the theoretical shift was important, as it allowed me to maintain a different professional knowledge and identity in the predominantly modernist environment of the hospital. In terms of my practice, the shift entailed a movement away from 'what I thought about what patients were telling me to trying to understand what patients think they are telling me' (Weingarten, 1998, p.4). This shift also involved a move towards what Weingarten calls 'radical listening', which permits 'the voice of the other to be heard' (1997, p.210). I therefore tried to develop a therapeutic posture of hospitality to the 'voice' and 'self' of young people and their families, which I considered important in a hospital setting where the title of 'patient' can de-humanise and undermine identity.

My new primary task involved working with sick children, adolescents and their families who were struggling to adjust to a new diagnosis or cooperate with harsh, mentally-demanding treatment regimes; working with anxiety, anticipatory loss, and loss of life through life-threatening illnesses; and the emotional and relational impact of illness on young people and their families.

Within a short time I became aware that a high proportion of the referrals for our service were from young people with MUPS. By the time they arrived at PLS many had been engaged with medical services for many months or even years in search of a medical diagnosis and cure, but with little or no success; leaving young people and their parents angry and frustrated.

MUPS can be common in childhood with a spectrum from very brief episodes to very severe. Parents can often contain the sometimes intensely felt symptoms in their child without a trip to the doctor or an accident and emergency department. The children and young people referred to our service are usually on the severe to very severe end of the spectrum and constitute the clinical population that stimulated my research interest.

Since I began work in PLS many healthcare professionals have also expressed frustration about patients with MUPS. They have requested referrals stating that they had exhausted all options in terms of treating the symptoms, that there wasn't much else they could try from a physical perspective and could only suspect that 'there must be something going on psychologically'.

We were often able to develop good relationships with some healthcare staff and collaborate on joint work with families, helping to introduce them to the kind of work we do in PLS. However, on other occasions, when this preparatory work wasn't done, the young person and families attended the service incredulous that they had been referred to CAMHS, declaring it was clear to see that their child was experiencing physical problems, "not psychiatric problems".

Some young people had extremely debilitating symptoms. One young person, aged 16, informed me she had been prescribed 48 types of painkillers, but the pain was still unbearable. She asked how we could possibly help since 'talking' about things didn't make any difference. Some young people arrived in wheelchairs, screaming with pain, while others were seen on the wards bedridden and passive.

As I engaged with young people and their families and listened carefully to their stories, I heard multiple descriptions of distress beyond that associated with any physical symptoms. Young people and their families often described feeling lost, abandoned by medical services and school/college, whom they perceived as showing little understanding or support, despite on-going symptoms and lengthy absences from education. Many young people had lost confidence and

described existential problems, while parents felt overwhelmed with their child's difficulties, which were preoccupying them and dominating family life.

I therefore decided that I could make an important contribution to the quantitative and qualitative research on MUPS that was being undertaken prior to 2006, which was in the main evaluative, and conducted largely with adults.

I constructed a research question aimed at eliciting first-person accounts from young people, parents and healthcare professionals in the hope of bringing forth stories which highlighted why MUPS sufferers were so marginalised and dislocated from medical and other institutions. Other questions quickly followed, such as what is the impact of MUPS upon young people's development, relationships and identity? What is the impact of MUPS on family life and relationships? What was the effect of not having a diagnosis? What role do institutional and wider societal discourses play in shaping personal/professional stories that can serve to reinforce MUPS sufferers' isolation? These are just some of the questions that arose within my own clinical practice, that I considered could be usefully explored in a research project.

The philosopher Charles Taylor (1994) draws attention to the damage people can suffer as a result of non-recognition by or from others, and his remarks on the importance of recognition and authenticity seem relevant to MUPS sufferers:

Our identity is partly shaped by recognition, or its absence, often by misrecognition of others, so that a person or group of people can suffer real damage, real distortion, if the people or the society around them mirror back to them a confining or demeaning or contemptible pictures of themselves. Non-recognition or misrecognition can inflict harm, can be a form of oppression (Taylor, 1994, p.25).

The impact of non-recognition or misrecognition is compounded in the experience of those who live with MUPS, in that significant aspects of their

experience is sometimes not given credibility by those with institutional authority.

Arthur Frank, Professor of Sociology, has devoted a large part his academic career – motivated by personal experiences of illness – to illuminate the stories of the ‘lived experience’ of those who suffer with chronic illness. Frank, (2012, 2010, 2004,1995) through a number of books and journal articles has been an inspiration to my practice, and has also provided me with a theoretical compass throughout the research.

Following a thorough reading of Frank’s work on illness and health I was able to identify connections on the experiential similarities and differences for those who suffer with long-term chronic illness and MUPS. Frank (2010) identifies the modern era as the period in which institutional recognition and misrecognition of illness is embedded with societal discourses.

My own practice has been influenced by McDaniel et al. (1997) who created a model for Medical Family Therapy practice. This team suggested that therapy can be greatly improved if the therapist is able to link with her/his personal stories of illness. I share the team’s belief that having a good capacity for self and relational reflexivity can serve to humanise the researcher’s emotional posture and increase his/her sensibilities to the plethora of emotions that often accompany the experiences of illness and disability.

Ethrington (2004) has pointed out that research students choose topics that will have some personal meaning for them, and that these connections will evolve over time and help to sustain their interest over the long period of isolated and often difficult processes. The above observation has had a resonance, as during the busy years of part-time study and work I continued to experience illness and loss in professional and personal life, and these events have reinforced my emotional connections and commitment to the research.

Before presenting a cross disciplinary Literature Review on MUPS as experienced by young people, parents and healthcare professionals, I was

mindful of the challenge for post-modern researchers when exploring the largely modernist dominated field of MUPS research. The following quotation, (Brown, 1990, p.188) helped me to clarify this dilemma:

One must use a known language to say anything intelligible, with its inherent vantage point and presuppositions. But it is difficult to convey a new vision in an established discourse. If the new perspective is too closely wedded to a new mode of representation, it will appear incomprehensible to the users of the old. But if the new vision is encoded in the old language, this very language although comprehensible may contradict the new message the author is trying to promote.

Keeping an eye to contradictions within and between both modernist and post modern paradigms it seemed important to be prepared to adopt a stance of irreverence towards my own ideas from my preferred theoretical standpoint and to be surprised when results are contrary to my theoretical assumptions (Cecchin et al., 1992).

Following a broad sweep of the literature on MUPS I will focus more closely on the postmodern approaches within interdisciplinary fields that connect most closely to the research question and my theoretical orientation.

CHAPTER TWO

2. Literature Review

My primary aim in this Literature Review is to introduce the reader to a broad cross-disciplinary selection of literature to enhance understanding of the research question and aims from different paradigmatic perspectives. It is organised in such a way as to illustrate how various sources have clarified my research focus and theoretical position.

My early literature searches revealed a large number of evaluative research studies and theories aimed at accounting for the experience of MUPS in adults, (from both medical and non-medical sources). There are fewer studies (referred to in this Review) exploring the experience of children, adolescents and families living with MUPS. The subjective experiences of adolescents and their parents/carers; their voices and stories were notably absent in the literature.

I have expanded this Literature Review to include the impact of living with chronic illness across the lifespan. I suspect that young people with MUPS will share experiences with the diagnosed group, particularly those with rare conditions. By extending the Literature Review to include the larger clinical population with chronic conditions, my aim was to compare and contrast research into the experiences between the diagnosed and non-diagnosed groups.

I have organised the Review into three sections, with intermittent reminders of the topics that have been covered, and reference to the relevance of the choices of literature to the research aims.

The first section begins with a discussion about the origin, definition and meanings attached to the term MUPS. The diagnostic features of MUPS for children and young people are then presented, prior to highlighting other terminologies from within a Western modernist paradigm that both pre-dates

and post dates the epithet. I then consider the 'contested illnesses' (Bulow, 2008, p.131) with a specific focus on Chronic Fatigue Syndrome (CFS) and its association with MUPS. I explore the prevalence of MUPS in childhood and adolescence in the U.K., and present a local audit from the Paediatric Liaison Service in which I work. The first part of the Review concludes with an examination of chronic pain and other symptoms associated with MUPS, and the impact of the condition on the lives of young people in the crucial phase of adolescent development.

In the next section, I will explore the literature on the effect of MUPS on young people, parents, and family. This is followed by the review of MUPS in the medical and healthcare literature relating to the experience of doctors and healthcare professionals who work with and manage young people and their families with the condition. This section includes a critique of the biomedical approach in general medicine and child and adolescent psychiatry (CAMHS), from both medical and non-medical sources. This section concludes with an exploration of cultural perspectives on MUPS.

The final section of the Chapter profiles authors influenced by post-modernist ideas from anthropology, medical sociology, cultural studies and narrative medicine; exploring the philosophy and critique of biomedicine's shortcomings in the social and cultural aspects of illness and MUPS. The final section draws together what Lynn Hoffman (2013) has called an 'assemblage of theories' from within systemic psychotherapy, with an emphasis upon concepts from social constructionist, dialogical and narrative perspectives, to aid in the understanding of the nature of experience and practice when applied to the field of MUPS.

A summary of the Literature Review with reference to the highlights and gaps in the field, which have informed the rationale for the research study, concludes the Chapter.

2.1 Reflections on the term MUPS

The term MUPS has increasingly been used within biomedicine and wider culture over the past two decades – following a series of natural disasters and the Gulf War, in which survivors and servicemen and women reported vague and non-specific symptoms. The term implies a social and clinical predicament, not a specific somatic disorder. It is rather drawing attention to a situation in which the meaning of distress is contested (Kirmayer et al., 2005).

I see this term as more neutral than a number of historical psychiatric diagnostic categories such as for example: psychosomatic; conversion disorders; hypochondria; hysteria and alexithymia; or medical terminology such as pseudo-seizures.

However, the term MUPS has its own set of limitations, and reflects the dominant Western medical culture which prizes scientific knowledge, and chooses to reduce challenging and difficult-to-comprehend phenomena beyond its paradigmatic boundaries into manageable terminologies. The term also seems unsatisfactory in that it reduces the suffering and trauma of experience into a dualistic binary linguistic phrase. Such an either/or denotation can also serve to obscure significant unexplained symptoms in diagnosable illness, and so too, much that could be explainable about MUPS.

In my clinical experience, MUPS is also poorly understood by young people and their families. Some young people and their families suggest the terminology is dismissive of their experience of symptoms, and not a term that they can utilise to describe or explain their experiences to others.

2.2 Diagnostic Features of MUPS in Children and Young People

I now explore diagnostic features of MUPS in children and young people from a psychiatric perspective, before moving on to explore terminologies from both medical and psychiatric paradigms.

Professor Elena Garralda (2004) a child and adolescent psychiatrist, has sought to raise the profile of children and young people with MUPS. She offers a clinical definition for MUPS drawn from epidemiological information (ICD-10) and also uses the term 'unexplained somatic complaints'. (Garralda, (2004, p.148) has identified the diagnostic features associated with MUPS in children and adolescents as:

- Physical symptoms which persist and remain unexplained following adequate examination, investigation, and explanation by a doctor.
- Frequent medical visits, despite negative investigations.
- Symptoms of depression and anxiety are common and can increase with the number of symptoms.
- Any physical symptom may be present.
- Symptoms may vary across cultures.
- Symptoms may be single or multiple and may change over time.

MUPS can relate to any part of the bodily system and has significance for all medical specialties (Brown, 2007). The most common presentation of symptoms includes headaches, seizures, abdominal pain, limb pain and paralysis, nausea and vomiting, muscle pain, fatigue (Gilleland et al., 2009; Garber et al., 1990 Campo, 2002) dizziness, backaches, loss of appetite and chronic pain (Konijnenberg et al., 2005).

2.3 Prevalence

Garralda (2004) reports that one in 10 children in the general population complain of recurrent physical symptoms – the majority medically unexplained – at some stage during their development. MUPS is a phenomenon that presents throughout the whole life span, but certain symptoms are more prevalent at different developmental stages. For example, pre-schoolers may present with abdominal pains, whilst headaches are more common in older children. Before puberty MUPS is reported equally between the sexes, while after puberty there

is a prevalence in females. Kirkmayer et al. (2004) report that MUPS account for 15 to 30% of all age-groups in Primary Care consultations.

In an unpublished paper (Slaveska-Hollis, 2013) undertook a review of 800 consecutive referrals to a hospital-based Paediatric Liaison Service. This case-based review revealed that just under one third of children and adolescents were referred with MUPS (Figure 1). Of this 190, 9.5% were described as having a dissociative disorder, 62% a somatoform disorder and 28.5% had other forms of MUPS (Figure 2).

Figure 1

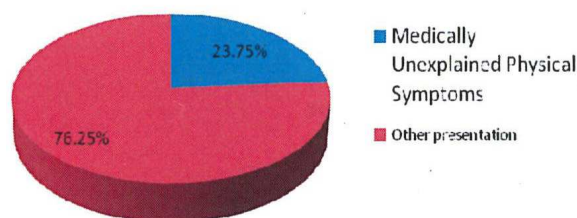
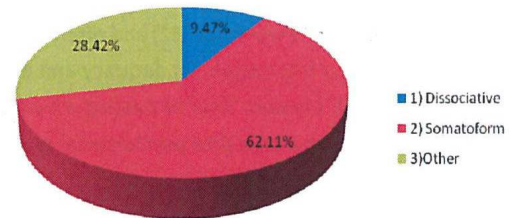


Figure 2



Although further studies of prevalence are required, the figures clearly demonstrate that MUPS is an increasing phenomenon in childhood and adolescence (see Appendix 1 for additional outcomes).

2.4 MUPS – A Multiplicity of Terminologies

There are drawbacks to living in a society with an increasing tendency to call all life's uncomfortable experiences disorders.

(Dr. Peter Hardwick, 2005)

The definitions of terminologies presented here are not definitive, but have been selected to inform the reader that, historically, many kinds of labels have been attributed to MUPS from within medical, psychiatric and psychological specialties. These terms have held various meanings in cultural and professional contexts during a succession of historical periods.

From a social constructionist perspective, some of the labels will be understood as being attributed to a personality trait such as 'psychosomatic'. Citizens in the general population will also attach multiple interpretations of meaning to these labels. Some older terms such as hysteria and 'malingerer' went out of fashion in professional language, but may remain in common usage, while other medical and psychiatric terms may be introduced to offer the next 'new' precise meaning to the experience of MUPS within the bio-medical paradigm.

From a psychiatric perspective the terms presume that psychological and affective factors account for symptoms. They may identify emotional conflicts, anxiety or depression, which the person is unable to confront and unconsciously displaces onto the body causing physical symptoms and resulting in somatisation disorder (Kirmayer et al., 2005). Garalda (2004) suggests that co-morbid psychopathology and mainly emotional disorders are common amongst children and young people with MUPS. She makes the distinction between ordinary emotional disorders and psychosomatic illness, because children and their families with the latter diagnosis hold disease beliefs and present with illness behaviour.

The term 'hypochondria' was first used by Galen in about 350 B.C. In the Middle Ages there were pilgrimages to shrines that were purported to cure certain diseases that had resisted the efforts of medical doctors (Sperling, 1978). The physician George Ernst Stahl (1702, p.20) was the first medic to identify 'the stupendous, sudden and quick effect of the so-called passions and affects on the body'. In pre-modern times a sick person was viewed as having a unity of mind/body/soul and treated as such with remedies of disease and illness.¹

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000) describes hypochondria as 'preoccupation with fears of having, or the idea that one has a serious disease

¹ Factitious disorder – when symptoms are consciously fabricated for the purposes of medical care, or Munchausen syndrome when a subject or parents move from hospital to hospital in search of medical treatment for their child, is not included in this study.

based on the person's misinterpretation of bodily symptoms and the preoccupation persists despite appropriate medical evaluation and reassurance'.

In a contemporary analysis of hypochondria Catherine Belling (2012) reintroduces the term into the cultural studies field. Her book opens with a more informal definition:

Hypochondriacs have two significant beliefs: that that their bodies contain something that will kill them and if they read their bodies closely enough they should be able to find that lurking threat before it is too late. If a doctor examines such a patient and announces that no evidence of disease can be found, the patient is not finally convinced. The patient concludes that this particular doctor is just not good enough to have found the horror that surely must be hidden somewhere. (Belling, p.1)

Hypochondria has been described as 'a diagnosis in search of a disease' (Lippsitt, 1973). The term generally has lost favour in medical circles if less so in common language usage 'our persistence in trying to retain such terms may lead not only to inappropriate application...but worse still to a stifling of investigations into complex conditions' (Lippsitt, 1973, p. 252).

The term psychosomatic also has historical origins and was introduced into medical literature by Johan Heinroth (1773-1843). In the modern era the term alluded to an interaction between the body and the mind, but in practice mirrored somatisation, a psychological influence on the body (Stone, 2009). Interestingly, Heinroth conceptualised the term as meaning body and soul, and believed that the soul had primacy over the body and caused many somatic illnesses (Steinberg, H., 2007).

The above terms gave way, to some extent, in medical vocabulary to Functional Symptoms Illness – a term engendered to describe a group of diseases which doctors found difficult to treat or explain. However, some authors have criticised

the introduction of such blanket terms, which do not assist patients and their families to recover.

In childhood and adolescence Functional Somatic Symptoms (FSS) are defined as physical symptoms of unknown pathology. 'FSS are associated with high levels of emotional impairment and co-morbid psychiatric symptoms such as anxiety and depression' (Beck, J., 2007, p.548). Beck has argued for viewing FSS as a continuum of severity rather than a discrete entity or diagnosis.

Somatisation disorder is a pattern of many physical complaints in persons younger than 30 years old that occurs over several years and results in unnecessary medical treatment and/or causes significant impairment in functioning. This diagnosis was historically referred to as hysteria (an ancient term originating from the notion of 'wandering womb'), or Briquet syndrome. The somatic symptoms are neither intentionally produced, or feigned, and appear to be unconscious to the patient (Spratt and Demasio, 2009).

Factitious disorder – when symptoms are consciously fabricated for the purposes of medical care, or Munchausen syndrome when a subject or parents move from hospital to hospital in search of medical treatment for their child, is not included in this study.

Peter Hardwick (2005) writing from a systemic perspective suggests that the term psychosomatic has drawbacks. He suggests there is a one-way link between mind and body, yet the reverse is also true, as physical illness can impact upon mental functioning. Bryan Lask (1989) introduced the idea of a psychosomatic spectrum, and suggests that all conditions are on a spectrum. Other family research practitioners have tried to introduce replacements for some of the above-mentioned stigmatising terms: bio-behavioural (Wood, 1994), or bio-psycho-social (Doherty, McDaniel, & Hepworth, 1994), but these have not replaced somatic terminology in the medical/psychiatric literature.

2.4.1 Pain disorder

According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR2000) pain disorder is characterised by pain in one or more anatomical sites and is of sufficient severity to warrant clinical attention. Common symptoms of pain disorder are: negative or distorted cognition, such as feelings of hopelessness, inactivity and passivity; in some cases disability; increased pain sometimes requiring clinical treatment; sleep disturbance and fatigue; disruption of social relationships; depression and/or anxiety. Acute conditions last less than six months while chronic pain disorder lasts six months or more. There is no neurological or physiological basis for the pain.

The diagnostic criteria also include distress and psycho-social factors which are judged to be a trigger for the initial onset of pain. The pain is thought not to be intentionally produced or connected to mood, anxiety or psychotic disorder. A diagnosis of pain disorder is not easily identified and is often dependent upon the physician being able to account for and explain the mind/body connection (DSM-IV-TR, 2000).

The term 'malingering' is not a psychiatric term and is used when the patient has a specific goal in mind when presenting with symptoms. Levenstein (1987) notes the pejorative connotations of the word 'malingering' for children and adults. It may be difficult to assess to what extent, if any, somatic complaints are consciously invented by the child or young person. Levenstein questioned the purpose of an assessment which would serve to expose a young person as a liar or a fraud. He preferred to consider why a young person found it necessary to manage problems or dilemmas in this way. Malingering however has become a part of common parlance and draws linguistic power from the antithesis of the Protestant work ethic. In my clinical work with young people with MUPS I have heard it used by a teacher to explain school absenteeism.

2.4.2 *Conversion disorders*

A study undertaken by Kozłowska et al. (2007) reports a complex picture of symptom presentations. In this study 55% of the cohort of young people (n.192) presented with multiple conversion symptoms. The most common symptoms were disturbance of voluntary motor function, sensory symptoms, non-epileptic seizures, and respiratory problems. The conditions appear to be more common in adolescents than in adults or children (Gold et al., 1995). Kozłowska et al. associated co-morbidity with depression, anxiety, pain and fatigue.

Two types of families that have been described as being predisposed to conversion disorder include families with anxieties about disease, and families that are prone to being disorganised. (Gratton-Smith P. et al., 1998) A dominant and conflict-prone parenting style is also associated with conversion disorder (Salmon et al., 2003). The onset of conversion disorder can be triggered by stressful family events such as divorce or death in the family. (Wyllie, 1999).

2.4.3 *Alexithymia*

Alexithymia is defined (Sifneos, 1969) as a personality trait characterised by difficulties in describing and identifying feelings; a limited capacity for imagination and fantasy; and externally oriented thinking rather than reflection on inner experience. People who are attributed the label of alexithymic are said to lack the awareness that symptoms could be caused by disturbed emotions. Subjects are considered to be vulnerable to incorrectly attributing innocuous physical symptoms to physical disease, and seeking medical care for symptoms for which there is no medical explanation. Such characteristics are believed to predispose people to MUPS. Sifneos (1973) reported that these patients tended to describe their lives in pragmatic ways.

Alexithymia has become an accepted area of interest for psychodynamic orientated clinicians and researchers. A growing literature has recently described alexithymic families, in which family members avoid emotionally close

relationships, or, if and when they do form relationships, these are described as 'superficial' with limited differentiation between self and others (Vanheule et al., 2007; Blaunstein, 1998)

2.4.4 Psychogenic non-epileptic seizures

Psychogenic non-epileptic seizures are events superficially resembling an epileptic seizure, but without the characteristic electrical discharges associated with epilepsy. The label 'psychogenic' suggests an entirely psychological explanation for symptoms. These seizures were previously known as pseudo-seizures but this term was substituted primarily because the 'pseudo' implied a lack of authenticity. There can be a dissociative aspect to these seizures and there may be significant similarities with epilepsy. It is important to emphasize to sufferers that they should not be seen by medical professionals as feigning symptoms or 'putting it on', and neither are they 'mad'. Triggering stressors or events may not be immediately obvious. 'Non-epileptic seizures' is currently a favoured term in paediatric neurology, but there is a danger that once the biological tests are completed the young person and family may be passed over to psychiatry or psychology, without joint transitioning or adequate explanation to sufferers.

2.4.5 Dissociative states or disorders

These are conditions that involve disruptions or breakdowns of memory, awareness, identity or perception, which are primarily thought to be caused by psychological trauma. Dissociation has many meanings but often refers to two particular experiences: de-personalisation, a feeling of disconnection from one's own body; and de-realisation, a feeling of disconnection from one's environment.

Dissociative states in childhood and adolescents are often believed to have their roots in childhood trauma involving loss or abusive experiences. Symptoms of dissociation may be difficult to diagnose or explain and there are careful attempts at developing a language that is closer to explicit medical

symptoms, thus 'pseudo seizures' and 'psychogenic' are dropped by some doctors who are in favour of 'non-epileptic seizures', perhaps due to stigma attached to the prefixes within a doctor's own mind, and in the language used by clinicians in explaining the condition to patients (Stone, 2012).

2.4.6 *Contested conditions*

In recent years there has been an emergence of what are termed 'contested diseases' in modern Western societies. As the epithet suggests medical opinion is undecided about these diseases, which are sometimes seen as synonymous with MUPS, in children and young people.

These diseases include post-viral chronic fatigue syndrome/myeloencephalitis (CFS/ME), fibromyalgia, repetitive strain injury, irritable bowel syndrome and whiplash. The syndromes are contested because their diagnosis is based on self-reported symptoms and cannot be verified by references to observable abnormalities in the body (Bulow, 2003).

In a study of disabling chronic fatigue (Farmer et al, 2006) undertaken with parents of twins, chosen as a neutral representation of the general child population in a large metropolitan area in the U.K. The researchers conclude that CFS/ME is not a rare condition in childhood. Sharpe and Wilks (2002) suggest the most common symptoms for children and adolescents diagnosed with in CFS/ME were lack of energy, needing to rest, multiple joint pain, and un-refreshing sleep. The authors suggested that from age 11 onwards young people have similar experiences of chronic fatigue to adults, and identified a link between disabling fatigue and depressive factors.

Pia Bulow's (2003) paper entitled *Patient School as a Way of Creating Meaning in a Contested Illness: The Case of CFS* is of interest to my research approach in terms of how the author employed discursive practices to CFS sufferers' accounts to create meaning in a situation of 'contested illness'. Bulow (p.227)

suggests the main reason for CFS being a contested illness is that diagnosis is received from subjective symptoms, which the patients report.

Aside from medically unexplained fatigue that is persisting or relapsing for at least six months, four or more of the following symptoms should be part of that report: headache, sore throat, painful lymph glands, muscle pain, un-refreshing sleep, post exertion malaise, and cognitive problems severe enough to cause a considerable decrease in activity.

Hyden and Sachs (1998) point out that clinicians cannot prove that a patient has CFS, and diagnosis is only finally reached through an 'interactive process' based upon the story of illness presented by the patient and interpreted by the physician.

What is relevant to the theoretical focus in the current study here is the notion that a young person will be given, or not given a diagnosis dependent upon how convincing the story presented by the young person or their family is. 'Therefore, stories are the most important (perhaps the only) possibility for the ill to claim illness' (Bulow, 2008, p.131).

Social constructionist and narrative theorists have critiqued the development of clinical diagnosis in psychiatry, particularly in relation to the Diagnostic Statistical Manual (DSM) which was conceived as a neutral scientific aid to assist empirical observation of 'natural' symptoms from within the discipline. In the next section I 'unpack' this critique, further highlighting the 'subjectivity' involved in medical interpretation and the vulnerability of a socially-negotiated diagnosis which frequently excludes family, social and cultural idioms of trauma and distress (Bendelow, 2009).

2.4.7 Reflections on terminologies

By exploring the different diagnostic terminologies which come under the umbrella of MUPS my aim was to demonstrate to the reader the complexities of biomedicine's ardour for diagnosis. Many of the symptoms, aetiologies and

treatments overlap, and some are left open between physician and patient to negotiate, with success often depending upon linguistic competency. In my view, the multiplicity of terms for mind and body problems are inadequate in reflecting the totality and uniqueness of the experience of MUPS sufferers and their families.

In common with other illnesses the history of terms to describe multiple symptoms associated with MUPS are drawn from medicine/psychiatry/psychology and common usage. This reflects the modernist temptation to pin down certainty by giving names to human concerns.

While a success of DSM-I (1952) over the last 60 years has been in its attempt to give definitions to life's troubles by means of scientific descriptions, a negative impact however has been to lead society relentlessly towards 'medicalization'; to fixate and isolate human problems, in turn driving the development of specialist clinics to treat discreet diseases. Paul Ricoeur (1976) has described the modern tendency to follow an unrealisable desire via diagnosis and medical interventions to make human concerns go away.

The dominance within contemporary medical and professional culture of DSM-IV-TR and evidence-based practice with their embedded discourses of assessment, diagnosis and best practice, have fitted with the contemporary pressures on public welfare budgets in Britain. The trend towards directing funding to approaches that link DSM-IV-TR and evidence-based research, continue to leave young people and their families who do not have a diagnosis increasingly isolated within both the medical and educational systems.

For narrative and dialogical therapists the medical focus on individual symptoms and decontextualized prescriptions raises questions about hearing the subjective client's voice and concerns. Locating problems within a client's internal psyche, as problems to be treated, can make therapists complicit in relegating dialogue or stories to a minor role, thus reinforcing unjust cultural practices that give rise to the labelling and deficit model. (Rose, 1990).

In the next section I explore what the literature tells us about the impact of MUPS on the lives of children and adolescents and how they experience the world.

2.5 The Experience of MUPS in Adolescence:

I surveyed the literature on children and young people's experiences of explained/unexplained pain, non-epileptic episodes, syncope and paralysis, in order to discover the impact upon development, psychosocial, emotional and relational aspects of living with symptoms. These aspects of experience will be relevant for children and young people with MUPS and their families.

Pain is defined by the International Association for the Study of Pain (IASP) as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or defined in terms of such damage' (1986). This is a limited and bland account, which emphasises the one-to-one relationship between pain and tissue.

Sifford (1997) offers a broader multidimensional definition of pain to include physiologic, sensory, affective, cognitive, behavioural and socio-cultural factors in an assessment a child's experience of pain. However, in many spheres of the medical profession I suspect the narrower definition remains dominant.

René Descartes (1662) created a model for the aetiology of pain, which came to be described as 'specificity theory of pain. This theory identified the transmission of pain as having one fixed pathway or centre; this came to be known as the stimulus-response model of pain. Over time the theory began to reinforce the mind and body split in Western medical epistemology, although I doubt this was Descartes original intention.

Mason (2004) refers to Melzack and Wall's seminal work on the *Gate Control Theory of Pain* (1965). He describes their work as a theoretical context marker for integrating physiological and psychological explanations of pain. Melzack

and Wall's theory stipulated that the relationship between injury and pain is highly variable and that innocuous stimuli may produce pain. The location of pain may be different from the location of a wound and pain may persist in the absence of injury after healing.

Griffin and Christie (2008) acknowledge that fatigue, headache, stomach ache and back ache are extremely common complaints in adolescents. Chronic pain without an identifiable organic basis occurs in 4 to 15% of a normative adolescent population. Influenced by the ideas of Griffith and Griffith (1994) they coined the term 'body talkers' to describe this group of young people who have complex presentations. They also found that these same young people could be very attuned to the non-verbal communications of health professionals, thus also making them adept 'body readers' and 'skilled at picking up on negative or pathologising attitudes' (p.535).

The absence of organic evidence of disease may lead health and education practitioners to the assumption that the patient is either malingering or that their symptoms are 'all in the mind'. Other studies have looked beyond the mind/body and suggest that MUPS has a complex aetiology in adults, children and young people. These studies have sought to link MUPS in adolescence with psychological disorders (Campo, Bridge, Ehmann, et al., 2004; Egger, Costello, Erkanli, et al., 1999), social deprivation, stress and family dysfunction (Burton, 2003; Craig, Cox and Klein, 2002).

2.5.1 Developmental theories of pain and other symptoms

In developmental psychology there have been a number of studies that have focused upon children's and young people's beliefs about pain and symptoms. Many of these studies, which set out to assess the cognitive views of pain, discovered that children who experience illness or hospitalization used more 'affect' words to describe pain than healthy children (Savedra et al., 1993).

Bibace and Walsh (1980) using Piaget's *Concepts of Developmental Stages in Cognition*, suggest that children have different ways of thinking about pain at different stages of the lifespan. Children at the concrete operational stage are known to often also see illness as caused by bad behaviour, as well as germs. In terms of emotions and relationships children at the concrete thinking stage seem concerned with *how* people become ill rather than what is happening inside the body. There is a desire for explanations about illness, which are best understood in metaphorical or analogous terms, i.e. the heart as a pump. The absence of explanations for children with MUPS adds to distress and uncertainty. The researchers present the beliefs of the 11+ age-group (abstract thinking) in less detail and largely in terms of cognitive competency. The older group are able to construe hypothetical events and understanding of physiological and psycho physiological explanations of bodily functions.

This study provides useful information about children's thinking about illness for those working with pain in children. It also takes a homogenous view of cognitive development and understates the implications of abstract thinking and affective implications for young people from 11 years of age onwards.

Beales (1983) interviewed 75 patients between 7 to 17 years, using drawings as the medium and a vehicle for obtaining information about their subjective experience of chronic arthritis. The younger children use concrete language to explain their pain, such as 'my fingers ache', or 'I can't move my neck properly' for motor restrictions. The older group had a better understanding of bodily structures and processes, but expressed a greater array of emotions about their illness than the younger group; such as fear, worry and sadness. The older group was more inclined to view illness as also a hidden disease 'unseen' process.

The above studies are useful for healthcare practitioners who aim to have a 'holistic approach' and attend to cognitive and emotional development in childhood and adolescence, in order to adapt their communication styles when explaining complex information to children and families with chronic illness and MUPS.

These studies are also of use for the current researcher in terms of MUPS having its onset in childhood and progressing into adolescence. It would be interesting to have cognitive studies on idiopathic pain, with the additional focus on the impact of social relations and language development upon cognition.

Equally, it is important to consider the difficulties for young people to access an emotional language with which to adequately describe their experience of symptoms. In the next section I consider the limitations of language to describe pain in conversion disorders and dissociative episodes.

2.5.2 *Limitations of language to describe pain and other symptoms*

Objective definitions of pain can appear distant from the subjective experiences, which often appear resistant to explanation due to the limitations of language. 'English' writes Virginia Woolf (1926) 'which can express the thoughts of Hamlet and the tragedy of Lear has no words for the shiver or the headache.' (Woolf's description of pain almost certainly translates for most languages.)

The theme of 'unshareability of pain' is developed in Edith Scarry's seminal work *The Body in Pain* (1985, p.12):

There is no language for pain...it resists verbal objectification...in the pressure to eliminate pain fragmentary language is available to those who are in pain and to those who wish to speak on their behalf. However the verbal sign can be inherently unstable and limited as daily patient/physician interviews would reveal. To have pain is to have certainty-to hear about pain (particularly in the absence of wounds or cries) is to have doubt.

From a practice perspective Melzack and Torgenson (1971) recognised the limitations of vocabulary to adequately describe the intensity of pain. They therefore developed the *McGill Pain Questionnaire*, to assist practitioners in the assessment of pain.

The connectivity between ‘lived experience’ and accessibility of a language to describe subjective experience is relevant to this study. William James (1890, p.169) suggests ‘language works against our perception of truth’. Brockmeier (2008, p.26) elucidates James’s original premises:

Language tends always to give more stress to single terms (to substantives in particular) than to both the relations and transitions among them and to the feelings that accompany our experience of them. While the stream of consciousness is essentially a process of one substantive part to the next, language (particularly English language) revolves around nouns continuously suggesting what James called ‘substantive’ conclusions.

The conclusions drawn by William James, and others who developed his thinking, is that language continuously fixates and isolates from streams of perception and consciousness, and as such the limitations of language are ultimately responsible for the gap between language or narrations, and some domains of ‘lived’ experiences.

Heidegger in *Being and Time* (1962) saw the ‘poetic or metaphorical elements of language as helping to draw us closer to the ephemeral aspects of the human condition, whilst seeing the reductionist aspects of language as favouring scientific enquiry’ (Brockmeier, p.26).

In the absence of young people’s first-hand accounts of pain and symptoms it is useful to turn to autobiographies by adults who have suffered long-term pain, (Biro, 2010; Greenberg, 2009; Heshusius, 2009). These authors have shared in common the ‘all-consuming’ nature of pain. Biro defines pain as an ‘all-consuming internal experience that threatens to destroy everything except itself – family, friends, language, the world, one’s thoughts, and ultimately even one’s self’ (Biro, 2010, p.18).

Each of these authors, in different ways, link with Heidegger’s premise that poetic or metaphorical aspects of language have value in drawing out meaning from the less tangible aspects of life. Heshusius (2009, p.111) writes, ‘A stain.

The metaphor shocks me because I know it to be so'. In this sense the metaphor of chronic pain is presented as a stain that remains on all those who come into contact with it. This metaphor succeeds not in a fleeting or ephemeral way, but in its capacity to metaphorically represent aspects of the relational contamination of pain and illness.

Frank (2010, p.2) comments on Biro's mission in respect of utilising metaphor for those who live with pain, is to introduce the 'range of metaphoric use and thus reverse the inward pull of illness'. The experience of loneliness as a consequence of living with pain is identified by Heshusius (2009, p.10) who remarks, 'You are so alone in the pain experience...you begin to feel that nothing outside of the self can be grasped anymore'.

In relation to adolescent MUPS sufferers and their parents I wonder if sometimes the certainty and stultifying language of biomedicine, within the medical encounter for example, stifles the opportunity for metaphorical exchanges between patient and physician. However, Brockmeier (2008, p.27) reminds us of the countervailing qualities of language to 'fixate' and separate aspects of our consciousness and experience:

Language offers us the opportunity to think and reflect on the first meaning to experiences, thoughts, emotions and moods; to communicate and engage in dialogue about their meanings; to reach out to others and to open up to those who reach out to us.

Mason (1999) emphasizes that experience of pain is almost always in the context of relationships. His focus is based upon a personal history of chronic pain and research into pain in adulthood. He shares his experience that 'During my many years as a patient, conversation never went beyond me and my condition, yet I was only too aware that my condition influenced and was influencing those close to me' (p. 9).

This experience could be familiar to parents of older adolescents who may sometimes be excluded from medical information or from participating in an open dialogue in medical/social care planning due to rules about confidentiality.

In summary of this part of the Review, I have focussed upon the impact of explained and unexplained pain and symptoms on children and adolescents. I have highlighted studies that considered child and adolescent stages of developmental understanding, and perceptions of illness. I then considered the challenges for children and adolescents in accessing language that adequately describes how they experience pain and other symptoms due to the limits of language itself. I conclude this part of the Literature Review by presenting extracts from first-hand accounts of adults who live with chronic pain and identify metaphor as a feature of language with the potential to bring forth meaning and healing of pain. Under the next sub-heading I consider the impact of MUPS on young people's development, relationships and emotional well-being.

2.5.3 'Falling Out of Life' and the impact of MUPS in adolescence

There can be multiple challenges for young people and parents/carers without a discoverable medical cause in terms of the impact upon the young person's educational, social and emotional development (Furness, et al., 2009).

Altschuler (1997) has identified a number of challenges for adolescents with chronic conditions, including MUPS. She suggests illness distorts the adolescent period because physical limitations increase dependency upon family and others, affects body image, self-perception, and sensitivity to the responses of others; including experiencing shame and embarrassment. The adolescent with chronic illness can fear the loss of abilities and restriction of social and sexual activity. Finally, pre-illness peer relationships can change or be severed completely.

The impact of MUPS can be hugely damaging to an adolescent's identity and future life plans. The young person is faced with the loss of academic and social experiences which are not always easily replaced and they can fall significantly behind their peers in one or both of these developmental areas.

Rangal et al. (2000) reports that when CFS/ME illness is at its worst, most young people stop socialising with their friends, and family relationships can become strained. Half of the young people in the study had been bedridden for long periods and some were in wheelchairs. MUPS had a dramatic impact on school attendance: two thirds had been completely absent from school and the mean time out of school was one year. Young people expressed beliefs (which persisted after recovery) about the presence of disease despite medical evidence and re-assurance about future health. Young people may lose confidence in their ability to socialize and perform educationally at their previous (or aspired) levels of achievements.

Konijnenberg et al., (2005) also report that young people with unexplained chronic pain suffer substantial impairment in everyday life. School attendance is dramatically reduced and young people experience difficulties with sleep and a sharp decrease in physical and social activities. Garralda, (2004) wonders if withdrawal and passive, reduced coping strategies may be ways in which the young person regains partial control in the face of powerlessness in relationships at home, school, or in peer relationships.

Hall-Lande et al. (2007) in a general study of social isolation upon psychological health refer to an increase in risk for young people of depressive symptoms, suicide attempts and low self-esteem. The authors highlight protective factors to militate against these risks. For MUPS sufferers and their families, introducing protective factors such as promoting family connections and building healthy peer relationships may be unrealistic, due to the practical and emotional dislocation of adolescents and their families from institutional understanding and support, and the negative impact of the dominance of symptoms on family life.

A family who live with MUPS may add to their social isolation by the necessity to demonstrate internal solidarity of family members against the mistrust and perceived threat from the outside world. However, this demand for internal loyalty may leave little room for manoeuvrability or appreciation of difference within family relationships.

Family life and routines can be disrupted by multiple journeys to and from hospital appointments. Many young people can repeatedly be referred for investigations and treatment, which serve to reinforce anxiety about physical disease. Furthermore, multiple symptoms can mean multiple consultations/investigations in a range of different specialisms.

In summary, the experience of severe and prolonged MUPS can have a devastating impact upon the academic, emotional, and social life of an adolescent. Young people can become socially isolated due to non-attendance at school or college. Their contact with friends and social activities are radically reduced, and family relationships can be stressful and 'frozen'. The adolescent with MUPS is vulnerable to a greater risk of anxiety, depression and self-harm due to social isolation, and protective factors are difficult to access because of disengagement or conflict with external institutions. I now turn to focus on the experience of parenting an adolescent with MUPS.

2.6 Parenting Young People with MUPS

As a preface to the exploration on parental experience of living with an adolescent with MUPS it is important to draw attention to Altschuler's (2012, p.69) observations that 'an increased proportion of children live in one-parent or three generational households, or with parents who are not married and/or in a same sex relationship, the majority of literature draws on studies based on married couples in a heterosexual relationship'. Each family constellation may have additional experiences unique to their particular circumstances, yet have similar challenges when parenting in the face of MUPS.

Parenting, like most of life's experiences has its ups and downs. Parent and adolescent relationships can be changeable and unpredictable as part of the developmental stage. Parenting a child with chronic illness or MUPS will have additional intense feelings of loss, doubt, ambiguities and insecurities about planned or imagined futures. In many families such doubts and feelings are less likely to get ventilated due to reasons both internal and external to family life.

As Altshuler (2012) has noted, finding your child or adolescent ill can be highly distressing and in some situations traumatic, but to then be told that the cause is unknown and medical treatments will be ineffective can bring additional anguish to parents.

Judd, (1995, p.91) writing specifically about chronic illness suggests it is

...not unusual to hear parents of children who are ill talking as if they were the patient: not being able to think, feeling chaotic, developing a range of symptoms, losing their memory, 'feeling shell shocked', 'going to pieces', 'walking into walls', feeling 'gone' and 'living day-to-day'. Clearly they are sparing their child some of the impact by being in the 'front line of the battle' themselves.

The interactions and relationship between a sick young person and their parents in decisions to seek, or not to seek medical treatment, are important precursors to engaging with a medical practitioner. Therefore the perceptions, beliefs, and behaviour of a child's parents/carers combine with a sick child's communications in the decision to seek confirmation of illness outside of the immediate relationship (Turk et al., 1985). Hotopf's (2002) study highlights the mutual influence in the parental-child relationship. He found that childhood experience of illness in parents is a risk factor for the appearance of MUPS in later life.

Legitimization is a process by which people prove to themselves and others that their sensations and feelings truly represent sickness. This process can be informed by the wider societal discourses or narrative templates, as well as

immediate family responses, which may imply that the illness or symptoms are imagined, emotional or psychological.

Telles and Pollack (1981) identified several stages in this legitimization process, in the family's attempts to verify the authenticity of the illness by asking friends, family and colleagues. The search for validation and interpretation of the seriousness of the symptoms finally leads people to a consultation with a medical practitioner. This research highlights the journey that families may have travelled in search of legitimization even before a visit to the doctor. Members of this familial consultation network will all have expectations as to the outcome of the physician's appointment.

2.6.1 Blame and self-blame in parents

Some parents may respond to the unexplained aspects, and the durability of the pain or symptoms in the young person, with increased stress and frustration, which then provokes negative patterns of interactions (self-blame and blame) within the family and in relationships with healthcare professionals.

Altshuler (2012) draws attention to blame and self-blame and sees these emotions as features in the parenting of children and young people with chronic illness and MUPS. Parents can be concerned about feeling criticised or blamed. The tendency to blame oneself for being ill (or the person who is ill) is more prevalent in adults. When a child or young person is ill, parents are more likely to feel accountable.

Unlike Altschuler, I would suggest that some children and young people with MUPS do feel blame and guilt about the distress their symptoms cause their parents. They may also feel 'in a bind' in that their fears remain hidden or are suppressed to avoid further disconcerting displays of emotions in a parent, or to preserve a genre or myth associated with how members should behave around illness.

Although with MUPS both parents can feel considerable responsibility for the well-being and integrity of their child, it is usually a mother or female carer who takes responsibility for the young person's care. The role of a single parent as the primary carer may leave less responsibility for the ill young person, partner, siblings and extended family members to share the responsibilities for the necessary adjustments when living with MUPS. There may be other reasons for the central involvement of mothers; including cultural mores, a closer attachment with the child and responding more empathically with their child's circumstances than others are able.

Altschuler (2012, p.20) highlights ascriptions of gendered blame in families who experience chronic illness, for example, 'Men are more likely to blame external factors and women to blame themselves'. Weingarten, (1998) has identified 'mother-blaming' as dominating the psychological literature, which underpins and directs healthcare matters towards women. I selected one particular study from the literature which provided a good example of mother-blame in relation to children with MUPS.

The study was aimed at exploring how mothers of children with MUPS manage their child's recurrent somatic symptoms. The researchers drew out three main themes, which emerged from a thematic analysis relating to 'making sense of the symptom', 'the impact of the symptoms', and 'strategies for managing'. The researchers abstracted three core issues in their analysis of the mothers' transcripts related to ambiguity, authenticity and responsibility from the transcripts of semi-structured interviews.

They concluded that when symptoms were ambiguous mothers made uncontrollable causal attributions that removed responsibility away from the family. Furthermore 'even when the mothers reported coping strategies that may have exacerbated their child's symptoms these were defended in ways to minimise their own potential influence and to emphasise authenticity of the symptoms' (Morris & Ogden, 2012, p.285).

The above researchers who appear to be theoretically situated within the post-positivism paradigm conclude that mothers of children/adolescents with MUPS in particular are culpable in terms of exacerbating symptoms and distancing the family from any responsibility for symptoms. The language used by the authors to describe the mother's responses is, in my view an example of mother blame.

A number of judgments in Alice Miller's book *The Body Never Lies* (2005) could be seen as 'parent blaming'. What strikes me about her narrative and the previous example is how language from some research and clinical traditions draws out a focus of features of a subject, parent or family, while obscuring other possible descriptions. The choice of language therefore reinforces an author's preferred way of thinking and acting towards problems – potentially excluding other possibilities. I briefly introduce the reader to Miller's ideas in the following section of the Review.

2.6.2 *Illness as somatisation – problem of parenting?*

Alice Miller, a renowned child psychologist, has written a number of influential books on the effects of child abuse upon children's biological and social development. In her book, *The Body Never Lies* (2005), she postulates that under the guise of moral parenting embedded in the Fourth Commandment, 'Honour thy Father and Mother' the true of self of a child is suppressed:

Physical illnesses are the body's response to its vital functions. One of the most vital functions is an ability to listen to the true story of our lives...the central issue is the conflict between the things we feel – the things our bodies register – and the things we ought to feel so as to comply with moral norms and standards we have internalised at a very early age. (Miller, 2005, p.36)

Miller develops the theory that where children are bound by fear to rigidly adhere to their parents wishes they repress their 'true feelings' in childhood. As religious and societal discourses are so protective of parental morality, even when in adulthood, the inner child remains hidden, due to fear of some dreadful

consequences. Miller offers a series of vignettes of famous authors; Dostoevsky, Chekhov, Kafka, Schiller and Woolf, all of whom she believes suffered from oppressive parenting. Despite attempts to expunge an inner turmoil through their writings they suffer bodily pain, while nevertheless continuing to idealise their parents throughout their lives.

Miller presents at times a forceful narrative, and in this and a series of other works, she has increased awareness of child physical, sexual and emotional abuse within the family.

There can be no doubt that some children suffer terribly from torture and unyielding oppression by their parents. However, Miller describes her concepts with a certainty that I find difficult to apply to young people, parents and families I have met clinically, employing powerful negative language about parent and child relationships. To apply Miller's hypothesis about the harm caused by parental beliefs to their children generally, would be incongruent for most health and social care practitioners who would probably see parents with a myriad of religious or social beliefs as 'good enough' parents, and whom they recognise, in an increasingly complex technological age, are having to constantly adjust to pressures whilst being surrounded by diverse and ambiguous discourses on what constitutes a 'good parent.'

In a paper entitled *Don't Blame It On the Parents – Make Them Your Allies* Gustafsson (2005) offers a positive construction of the role of parents. He argues for harnessing the resources of a sick child, parents and siblings and sees them as crucial allies of the medical team. This means avoiding blame and working with parents to understand the rationale for diagnosis and treatment. In the case of MUPS this may entail working with parents and other family members to jointly process the reasons for non-diagnosis, whilst remaining sensitive to distress and the veracity of the adolescent's experience of the symptoms.

Reflecting on the experiences of parents of adolescents with MUPS, I have highlighted in the Literature Review studies which appraised the initial

processes of evaluation of a young person's symptoms by parents and extended family relationships prior to any medical appointments. I also draw attention to the research of Telles and Pollack (1981) who identified various stages of the legitimisation process of a child's symptoms by parents or carers prior to seeking medical legitimisation of a doctor.

I have also cited Altschuler (1998) who has brought to our attention a range of emotions experienced by parents in response to child and adolescent illness; including deep concern, self-doubt, anticipatory loss, blame, and self blame. Finally, I critique two sources in the literature that attribute 'blame' to parents and particularly mothers, one by a child abuse expert and the other a qualitative research study, both of which use negative language and attributions of parents of children with chronic illness and MUPS. Such attributions contribute to narrative templates about the parenting role of sick children in wider society. I now explore the limited research on MUPS and its impact upon the family.

2.7 MUPS and the Family

The dearth of literature upon the experiences and the subjective 'voices' of family members living with MUPS highlights a gap in the field and suggests that the trend in qualitative research is toward individual rather than family studies. To date, I have come across no studies in the literature which have considered perceptions and experiences of parents/carers, grandparents and siblings living with a young person with MUPS.

However, there is research attention to the subject of illness and psychosomatic illness and the family by systemic, health science and narrative medicine researchers. In this part of the Literature Review I therefore examine research from both chronic illness and MUPS across the lifespan. I anticipate that the research from these sources will inform the reader about the impact of living with chronic illness and MUPS, thus allowing the reader to consider the similarities and differences as described in the available literature between the two experiences.

As the limitations of medical science became increasingly evident in aspects of illness and disease, research in the 1970s and 1980s witnessed an interest from researchers from the psych-social professions to demonstrate that non-medical approaches could facilitate therapeutic changes that biological medicine could not. Many of these researchers turned their attention to personal health habits and social influences on illness. At the same time a second generation of systemic family therapists were also organising a new discipline. Family Systems Medicine (Campbell, 1986; Fischer et al. 1992; Terry & Berge 1992) was developed to demonstrate how health and family life are related and how medical treatment can be delivered in a family context. Family practitioners and researchers studied a wide range of illnesses to determine relationships between health and family structure, problem solving abilities, illness beliefs, and styles of managing emotions (Campbell, 1986; Fischer et al., 1992; Terry & Berge, 1992).

In Family Therapy Minuchin et al. (1978) in a major study of psychosomatic families, found that the families of children suffering from such illnesses, i.e. anorexia nervosa, asthma, diabetes, were characterised by enmeshment (family members are over-involved with one another and over responsive), rigidity, and a marked inability to resolve conflicts.

Minuchin et al. (1978) suggested that the psychosomatically ill child may help the parents to avoid facing the conflict in their relationships by focussing all their attention upon the child. The child is unconsciously encouraged to remain sick in order to distract parents from having to face marital problems. Minuchin et al. (1978) also believed that physical symptoms may be used to maintain a dependent role in the family, while for others it may be an expression of frustration, anger and deprivation.

The work of Minuchin et al. (1978) was ground-breaking in that they extended theories of psycho-somatisation beyond a mind/body intra-psychic into the relational domain of family relationships and wider culture. The team's formulations based on observations and clinical experience directed their

theoretical lens towards patterns and interactions in family dynamics. However, criticism of the ethical practice of presenting formulations to families delivered with certainty and truth from an 'expert position' increased over time.

Coyne and Anderson (1989) offered a critique of the Minuchin et al. (1978) study of psycho-somatisation and the family. Drawing upon references to their own research on families who had a member suffering from brittle diabetes, they suggest that the Minuchin et al. (1978) model de-contextualises the family. They argued that the formulations of Minuchin et al., based upon family interactional patterns, could be viewed as the family's response to the disease process, the adjustment to illness, and the nature of the family's relationships with the healthcare system. They also question the claim of Minuchin et al. (1978) to have discovered a direct link between observed family patterns and individual physiology, without publishing the 'observational data'.

Coyne and Anderson (1989) called for a new 'open systems' model of the family's role in diabetes and chronic illness generally; recommending a greater focus on how families are engaged by the medical system and suggesting that more reliable data was needed prior to claiming certainty about the links between psycho/social issues and organic causes.

The notions of evidence for causative factors for MUPS in families and social networks remains important. However, in my view, qualitative researchers have given insufficient attention to first-person accounts of family members in order to abstract an understanding of their experience and narratives of living with MUPS.

Thirty years after the publication of the Minuchin et al. (1978) research, Christie and Griffin (2008, p.533), reflecting from a post-modern narrative stance critique their approach to psychosomatic illness, suggesting that

...labelling the unexplained symptoms as psychiatric, effectively shifts the cause onto family functioning. Families become defensive and hyper vigilant for criticism from the treatment team and less open to working

collaboratively. Parents often report that they feel blamed by teams for having caused the problem.

Recent studies have focussed upon the effect of debilitating symptoms in adolescents living with MUPS, which were found to impact significantly upon parents, siblings and extended family (Eccleston and Malleon, 2003; Perquin et al., 2001). Time and the experience for young people and families who live with MUPS is described by Eccleston and Malleon (2003, p.1408) as a 'diagnostic vacuum in which symptoms may be unmanaged and unrelieved'.

For most children the family environment plays an influential role in their response to, and perceptions of illness. Some studies however, have shown no difference in family characteristics between families of children with recurrent pain syndromes and 'well' families on measures of quality of relationships, marital satisfaction and parental psychopathology (Robinson et al., 1993; Walker et al., 1993).

Hardwick (2003) who had a special interest in MUPS sufferers as part of his paediatric liaison role added to the theory of 'family myths' (Ferreira, 1963; Byng Hall and Campbell, 1981) in terms of the myths associated with illness and medicine that can influence and shape family life and relationships. He suggested that when a family is stressed or misunderstood and tensions reach pre-determined thresholds their world view can become rigid.

In a study of 40 families Hardwick (2003, p.5) discovered a number of medical myths based upon false or distorted beliefs:

- The presence of a condition or fears of it arising
- Exaggeration or minimization of the severity of an established condition
- Recovery or lack of a recovery from a condition
- Manifestation of a condition
- Causation of a condition or of a condition feared to arise
- Treatment or management of a condition
- Transmission of a condition.

An example of a myth arising from the management of an unexplained condition may involve family interactions aimed at protecting the sufferer from further stressors, thus reducing activities and complying with the sufferers management of the symptoms at the expense of the wellbeing of other siblings and parent/carers.

In a later paper, Hardwick (2005) highlights the importance of engagement with families holding strong medical beliefs about the nature and treatment of their problems, despite contrary medical evidence. Hardwick's (2005) main focus is upon the therapeutic skills required to engage with what he terms as medicalising families who are actively reluctant to join with a psychological service. Hardwick (2005, p.607) believed that exploration with families 'commonly reveal illness beliefs and myths that maintain doubt and resistance to engaging and will need challenging and modifying; i.e. if it's psychological then it must mean we [the parents] are to blame'.

In this sense, the blame that parents feel may also have a source in negative family discourses about psychological and emotional distress. Feelings of shame or threat to the competency of parenting may underpin blame, which is reinforced by 'medicalising' and separation of mind/body distress by the hegemony of medical and social institutions, and social structures.

Hardwick (2005, p.603) grouped together a number of characteristics that he associated with somatising families which is of relevance to the current study:

- Over focussing on symptoms and illness with a sensitivity to physical discomfort
- Similar symptoms and illness in other family members (Hotopf et al., 2000)
- Difficulties expressing emotions and distress in a psychological way.
- Many children presenting with somatisation are 'good children', who are very compliant, conscientious, perfectionist and high achieving.

Medical events in the family history may need reviewing, as unresolved medical traumas or losses from the past can be re-played in the present. Hardwick (2005) recommends externalisation (White & Epston, 1990) of the symptoms (separation of self from symptoms) and encouragement by a therapist to develop emotional language; an introduction of a rehabilitative approach (which can offer an exit strategy for a child, out of illness behaviour) were all considered useful.

Hardwick (2005, p.609) also challenges idealistic beliefs in young people and their families under what he terms a practical philosophy approach, challenging the ideal of a stress free, comfortable and happy life with a quote from Confucius: 'Our greatest glory is not in never having fallen, but in rising every time we fall'.

Sometimes efforts may be made to hold on to patterns of pre-illness life. The family can become 'frozen' (Walker, 1991) in introducing old ways to minimize uncertainty, but this approach 'has limited relevance to current needs' (Altschuler, p.45).

In the absence of first-person accounts of MUPS sufferers, their parents, siblings, grandparents and extended family about their experiences of living with MUPS, I have presented research reports from the family studies and family therapy field. Many of the authors are very experienced practitioners in applying systemic family therapy concepts to a holistic family approach to chronic and unexplained illness. What they have 'unpacked' about relationships and the dynamics of families where one member had somatising problems continues to be of value and interest. These clinician researchers listened to family stories in the 'here and now' and expanded treatment options for psychosomatic problems beyond the purely medical and intra-psychic which had been dominant treatment approaches in the middle part of the last century.

As a post-modern researcher utilising narrative and dialogical concepts, this research presents a beginning to the exploration of parental experiences of living with a young person with MUPS. It is my hope that in the future I will, in

collaboration with others, undertake further qualitative research that explores the 'whole family' experiences of living with MUPS.

2.8 MUPS – A Doctor's Dilemma

In the previous sections of this Literature Review I have explored the literature related to the experience of MUPS for young people, parents and their families.

I now turn to examine the literature upon the experience of doctors and healthcare professionals in both primary and tertiary healthcare who are required to assess and manage young people who live with MUPS.

A broad literature search primarily revealed medical practitioners' work with adult MUPS sufferers, with a minority of papers addressing aspects of doctors' and healthcare professionals' views about young people and their families who live with MUPS. I considered cross-disciplinary literature that aims to explore the experience of doctors and healthcare professionals; present an analysis of the doctor-patient consultation; and explore the critique in the literature of a purely biomedical approach to MUPS. I conclude this section of the Review with my appraisal of the changes in the institutional discourses in CAMHS that make it difficult for MUPS sufferers and their families to access multi-disciplinary therapeutic support from these services.

Research into the impact of MUPS upon NHS staff has focused upon primary care. Wileman, May and Chew-Graham (2002) found that G.P.s were caring for patients, who repeatedly consulted them with symptoms for which they could find no clear physical cause. The G.P.s reported feeling stressed, anxious and frustrated, because of a lack of time to deal with the frequency and complexity of presentation, and a sense of feeling manipulated or pressured into referrals and investigations.

Wileman et al. (2002) also explored G.P.s attitudes to the management of stomach pain that presented as MUPS. The study found that G.P.s

unanimously accepted the concept of somatisation as a product of psychological distress. There was also minimal self-reflexivity demonstrated by G.P.s in terms of the part played by themselves in the medical encounter with patients:

I think patients think more in boxes than doctors do. If they've pain in their stomach then there's something wrong with their stomach...rather than it being a reflection of gut motility related to psychological distress. (Wileman et al, 2002, p.180).

In the above study negative judgments about patients dominated the G.P. accounts. Some G.P.s believed that patients had time to develop a view of their problems but had no awareness of the doctor's heavy workloads and time constraints. From the doctors' perspective patients were seen as dominating and directing the course of the consultation and therefore had real power. (Wileman, et al., 2002)

The study suggested patient dissatisfaction with care and on-going concern about physical disease, combined with practitioner stress and frustration, can result in potentially harmful deterioration in the relationship and communication between the G.P. and his/her patient (Wileman et al., 2002). Rosendal et al. (2005) highlighted the importance of improving communication, and suggested that practitioners may need extra skills and training to maintain a successful relationship with patients with MUPS.

Hartman et al. (2009), adopting a focus group method of data-gathering, found that G.P.s recognised the importance of an adequate explanation of the diagnosis of MUPS but often feel incapable of being able to explain it clearly to their patients. They try to reassure patients in non-specific ways, by saying there is no disease, the use of metaphors and by normalising the symptoms.

These studies give an indication of the potential for incongruity in the communication between MUPS sufferers and physicians in the medical

encounter. I shall now turn to examine the critique of these practices from authors inside the medical profession.

2.8.1 Critique of the biomedical approach

Other researchers from within the biomedical paradigm have commented upon the limits of modernist science when applied rigidly to MUPS, and have acknowledged a role for psycho-social therapies in assessment and management of patients.

Deary (2005) suggests that the meanings associated with the term MUPS are distorted by a culturally prevalent dualism where symptoms are either real or psychological. He traces the philosophical and scientific nature of Cartesian dualism with its evolution towards an increasing interaction between mind and world. He proposes that symptoms become far less inexplicable if one applies a new ontology more closely linked to a cognitive behavioural world-view.

Wilkinson (2005, p.22), conducting research into MUPS with adults, suggests that the mind-body dualism has led the medical profession to focus narrowly on the features of physical pathology. This has resulted in the neglect of the extent to which the subjective experience of pain and suffering is 'shaped by culture and moderated by the quality of our social relationships'.

Nimnuan et al. (2000, p.25) assessed risk factors affecting the provisional diagnosis of MUPS, made by physicians in new patients in 526 clinical encounters. The researchers were able to reflect upon the shortcomings of dividing MUPS into a simplistic duality. 'In reality there are psychological contributions to the experience of even the most organic medical condition whilst there are many physiological explanations for so called unexplained symptoms.'

A further finding was that a doctor's perceptions of the medical encounter have a strong influence on the diagnosis made and negative perceptions of the interactions are more likely to lead to the doctor diagnosing MUPS.

The above authors have highlighted limitations in doctors' adherence to a purely biomedical model in the assessment and management of MUPS. Engel Jnr. (2000) describes MUPS as medicine's 'dirty little secret'. He cites medical trainers who continue to teach their medical trainees that a biomedical assessment comes first, and to view MUPS as a symbol of personal failure to determine a diagnosis, or the patient's failure to overcome a seemingly benign challenge to their health. I suggest Engel Jnr.'s choice of strong language is designed to undermine a dominant discourse that doctors or medicine can 'cure all' diseases given time, and that MUPS remains hidden because it destroys the myth that doctors are able to make most of our ailments better.

The literature above, highlighting G.P.'s views of their experiences in medical appointments with patients with MUPS and the subsequent critique of the doctor's role, exposes gaps in theory and practice with MUPS patients and would suggest that a much higher profile in medical training and continuing professional development should be established within the medical profession. An important focus should be upon theory-practice learning on the interactional processes in the medical encounter.

I shall now turn to consider some other theoretical frameworks from the literature that assist thinking about the incongruence in the doctor/patient relationship where MUPS is concerned.

2.8.2 The doctor/patient consultation

Tannen and Wallat (1999) utilise sociological concepts of interactive frames (Goffman, 1974) and knowledge schemas (Heidegger, 1962) in their study of medical consultations.

The concept of frame refers to the definition of what is going on in an interaction, without which no utterance or gesture could be interpreted. The researcher's introduce Bateson's (1972, p.180) example to clarify the term:

A monkey needs to know whether a bite from another monkey is intended within the frame of play or the frame of flight. And so with human interaction whereupon the speaker and listener are confronted with the same interpretative task; to be aware of which frame is intended. A conflict of frames can cause misunderstanding about people, objects, events and settings in the world as distinguished from alignments being negotiated in the world.

Tannen and Wallerstein (1999) employ the term 'knowledge schema' to refer to the expectations of participants within any given interaction: 'even the literal meanings of an utterance can only be understood by reference to a prior knowledge...the only way anyone can understand any discourse is by filling in unstated information which is known from prior experience in the world' (p.349).

Tannen and Wallerstein's (1999) research highlights the mismatch of knowledge schemas in the doctor/patient consultation which 'frequently trigger parents' recurrent questions, which in turn require the doctor to interrupt the examination frame and switch to a consultation frame.' (p.363) The switch of positions by the doctor to a 'consultation' position (remaining meta to the process) can be received by the patient as a source of irritation, and a feeling that doctors' comments in this frame are distant from their story and experience.

2.8.3 The medical encounter – perspectives of the young person and parent

In terms of young people's experiences in the medical encounter one has to look to authors outside of the medical profession for views that reflect upon the patient's position and processes within the medical interview. The philosophers Carel and Kidd (2014) drawing upon a paper by Miranda Fricker (2007) offer an analysis of the doctor/patient consultation.

Carel and Kidd's (2014, p1007) arguments seem pertinent to young people suffering with MUPS when they observe that,

patients can suffer testimonial injustice, because they are often regarded as cognitively unreliable, emotionally compromised, or existentially unstable, in ways that renders their testimonies and interpretations unreliable. Furthermore, they may also suffer hermeneutic injustice because aspects of their illness experiences are not easy to communicate within restrictive social norms.

The young and elderly population may be disadvantaged in the medical interview as their voices may be unheard or ignored; with the physician relying on parental accounts or, in the aged – who may have declining intellectual faculties – the accounts of carers.

From the young person and parental perspective, healthcare professionals are seen as 'epistemically privileged' (Carel and Kidd, 2014) by virtue of their training, expertise and third person reports about the patient's history. Healthcare professionals by virtue of the power invested in them by institutional discourses/practices, are free to privilege their preferred styles of communicating about illness, utilising certain forms of evidence and perhaps being oblivious or ignoring other evidence. They may also choose to believe and utilise a third-person report over a patient's efforts to share their testimony and hermeneutical stories based upon their 'lived experiences'. The concepts of testimonial and epistemic injustice can naturally lead to conflict in the doctor/patient consultation. Wainwright et al. (2006, p.72) whilst recognising the success of medical science in curing diseases, suggest that 'in non-specific illnesses such as MUPS the biological reductionism of clinical science is of less value and can lead the clinician (and the patient) adrift in a domain of uncertainty and risk'.

A doctor's role is further complicated by professional, legal and cultural discourses in terms of what constitutes an appropriate response to human suffering. If Wainwright et al. (2006) see the expectations upon doctors as

idealistic and excessive, Porter (1997) adds weight to the counter discourse, suggesting that failure to find pathology does not mean pathology is not present. He also points out that the failure of detection of an organic cause for symptoms can have serious consequences for the medical professional in terms of scrutiny of practice standards and the possibility of litigation being brought by patients.

Risk and failure narratives have impacted greatly upon the professions in the last 30 years and healthcare professionals are particularly vulnerable to complaint and litigious claims. The pressures upon doctors to locate disease and illness have increased as medical technology has become extremely advanced in detecting the cause of symptoms.

In the next part of the Review I look at studies that have reflected upon medicines technological advances which although beneficial in terms of restoring physical health could be viewed as a reason for distancing a doctor from person-centred care.

2.8.4 The parts are greater than the sum of the whole

Toombs (1992) identifies the increasing technical sophistication of the role of physicians, which must impact upon their knowledge schemas. Toombs suggests that the physician is trained 'to perceive illness as essentially a collection of physical signs and symptoms which define a particular disease state. The patient does not 'see' one's own illness as primarily a disease process, but experiences illness in terms of its effects upon everyday life' (p. 92).

The reinforcing of the doctor's role as clinical expert has increased with the advances in medical technology and with the advent of MRI imaging which can show the source of the disease more speedily and clearly. Toombs points out that in modern medicine through years of training the doctor is taught to focus upon the part as representation of the whole.

Dena Stahl (2013, p.56) succinctly highlights the processes within the contradictory frames of the physician and patient:

Whereas the patient understands illness in its immediacy, through its interaction and coherence with her body, the physician seeks to categorise the illness into objective data, abstracting the illness for the patient so as to scientifically analyse it.

I considered if these concepts were more relevant to hospital specialists and care but I suspect the outcome is similar in primary care; on the face of it, the doctor and patient appear to be attending to the same issue, though they appear to be each holding a different view of the patient's body; and therefore they sometimes fail to develop a coherent meaning of illness.

The search for a coherent meaning is doubly difficult in the dialogue between physician and young person with MUPS, since from the physician's perspective there is an absence of medical evidence based upon a physical examination, and often multiple investigations designed to locate disease. Toombs (1992, p.92) proposes an alternative approach by the physician 'if the physician is sensitive to the patient's interpretative understanding of illness, he or she can act as an arbiter of meaning-perhaps enabling the patient to modify or to change an inappropriate interpretation of the situation'.

In some circumstances the reporting of a clean bill-of-health as a result of medical testing will be a relief to young people and parents with MUPS. However, in other cases such information may be also received negatively; by parents and young people who continue to be concerned they have not been taken seriously, or by any implication that the patient has been wasting health service time or that their child is 'malingering'.

2.8.5 MUPS sufferers in hospital

Increasingly MUPS sufferers' symptoms are so debilitating that they require hospital care. Furniss, et al. (2009) explored hospital staff perceptions of MUPS

in children and young people. The study revealed some awareness of the complexities in working with MUPS, which places extra demands and anxieties on healthcare staff with regard to time management, care protocols and communication. Paediatric healthcare staff interviewed looked to CAMHS for more information and training on how best to care and manage MUPS sufferers who require inpatient assessment and care.

The anthropologist Lock (1993) comments upon the culture of the hospital; in which the focus is upon the care of the body, and individual distress is systemically transformed into the decontextualized signs and symptoms of biomedicine, or is alternatively psychologised without reference to the part institutional discourses and practices play in triggering distress.

It is often a challenge to keep mind/body/culture thought and understanding alive in a hospital setting where the immediacy of symptoms, physical monitoring and care takes precedence. Access to perspectives from medical anthropology can open doors to the ways in which culture and language shape approaches to the care of the body and illness.

My subjective experience of working with hospital paediatric staff is that there is mixed appreciation that young people with MUPS may require time to be carefully listened to before they begin to feel more understood and trusting of professionals. Other factors in healthcare professional roles often militate against collaboration and therapeutic engagement with MUPS young people and their families, including heavy workloads, prejudices linked to explained and unexplained illness, and perceptions of the work as 'beyond their remit' and best undertaken by 'expert' psychologists or specialist teams.

It will be interesting to hear healthcare professional's accounts when faced with the kinds of dilemmas introduced above in the focus groups with doctors and healthcare professionals from the hospital setting.

In the past the presentation of MUPS, often with an attached label of conversion or functional disorder, may have come under (CAMHS) through which the

young person and their families would have had access to MDT therapeutic support. With the development of CAMHS PLS hospital teams, there may have developed a perception by CAMHS managers and commissioners that MUPS is PLS business. However, these teams are far too small to capture a large and growing clinical population. In the next part of the Review I reflect on some issues that may be excluding MUPS sufferers from these services.

2.8.6 The pendulum has swung towards biomedicine

In summary, I have presented literature that has examined the experience of doctors and healthcare professionals in general practice largely with adult MUPS patients, the processes within the doctor/patient consultation and a critique of biomedicine's technological advances and the impact upon holistic and hospital care. I shall now review the literature on MUPS in CAMHS with particular attention to how changing clinical and managerial discourses and practices within CAMHS institutions could potentially lead to the exclusion of MUPS sufferers from these services.

Garralda, (2004) has reviewed research on the interface between mental/physical health and medical help-seeking in children and adolescents. Garralda's study is aimed at broadening the theoretical understanding and the requirement of an MDT collaborative approach for work with MUPS sufferers and their families. She views MUPS as an expression of somatisation or the manifestation of psychological distress through physical complaints.

As well as raising the profile of MUPS in CAMHS Garralda has highlighted the mind/body unity in physical illness, during a period when the biomedical paradigm in CAMHS has been a dominant. In my view her research on children, young people and their families who suffer with MUPS has not led to clearer care pathways or easier access to MDT CAMHS intervention for young people and their families who have suffered severe symptoms for six months or more.

Garralda (2010) whilst acknowledging that the psychiatric expertise assessment and management of MUPS varies considerably and can be limited in CAMHS,

identifies Paediatric Liaison teams as ideally placed to deal with MUPS. These teams were traditionally situated at the interface between physical and mental health. Garralda (2010) also suggests successful engagement with these teams is dependent upon young people and families being able to appreciate the link between physical and psychiatric services and declare a willingness to consider psycho-social factors, along with the biological, if they are to begin to benefit from these services.

It is possible that psychiatric terminologies and language may trigger associations with stigma and culpability, causing problems for young people and their families with MUPS and affecting their engagement with CAMHS. Some authors have critiqued the mind/body model in child psychiatry in terms of its capacity to accommodate phenomena such as MUPS and the need to draw from non-medical paradigms in order to enhance understanding. (Lask and Fosson, 1989).

Child (2000) explores the strengths and limitations of the biomedical model as it has been applied in CAMHS. He observes a preference within CAMHS to travel a biomedical route. He recommends looking to non-medical disciplines that see a child's behaviour as a form of action or reaction to trying to solve problems in relationships and social systems, such as the family and school. In support of this view there is an evidence base that links bio/psycho/social processes to the understanding and management of MUPS (Greenfield, 2003; Eisenberg, 2000).

Hardwick (2005) pointed out the pendulum has swung between mind/body and biomedical approaches in CAMHS practice over a number of decades. In the present CAMHS culture the pendulum has surely swung towards biomedical principles and practices.

The political and cultural influences upon health and social care over the last three decades has resulted in greater emphasis upon individualised packages of care based upon diagnosis DSM-IV, ICD-10 and treatment in health and social care. The National Institute for Clinical Excellence (NICE, 2005) although increasing the profile of a range of conditions in young people's emotional and

psychological health, have appraised discreet evidence-based knowledge in clinical practice, demanding clearer identification of the skills and knowledge that each profession/al model delivers. The results have directed practice towards individualised care plans and treatments.

These trends in CAMHS have served to strengthen the boundaries of each profession, leading to raised referral thresholds and emphasised first order assessments and treatment packages for discreet labels of psychiatric disorders which an individual needs to have as 'a ticket' to access the services on offer.

I wonder if this culture has significantly reduced the practice and perceived necessity for open co-constructed dialogue and flexibility between professionals, when faced with challenging and difficult circumstances facing young people and their families; as each professional endeavours to define and preserve the parameters of their respective professional tasks and expertise.

These trends have also brought about an increase in specialisms in child health and CAMHS, largely based around separate individual physical and mental health conditions: i.e. bi-polar; eating disorders; and diabetes. The growth in specialisms, whilst concentrating knowledge, skills and training and generally improving the quality of care for the respective clinical populations, also leaves gaps in services for a number of other distressing co-morbid conditions such as MUPS, which do not fulfil the criteria of a single symptom/treatment modality.

However, there remain pockets of practice and theory, which suggest that the pendulum could swing again and build a more holistic approach to how services are delivered in CAMHS and Psychiatry. I offer two examples: first, Dr. Bradley Lewis' work on introducing narrative concepts into adult psychiatry 'Lewis's interest is to build a big tent within which the contributions of each perspective are welcome, and the only rule seems to be that everyone has to acknowledge that any way of practicing is only one perspective' (Frank, 2012). Secondly, and with particular reference to MUPS in childhood, Dr. Kasia Kozlowska, (2007) Child and Adolescent Psychiatrist and Team, Westmead Hospital, Sydney, has

built an reputation for high quality clinical and research practice with children, young people and their families with MUPS, whose expertise draws from family orientated multidisciplinary team approaches as part of an inpatient and outpatient service to this otherwise marginalised clinical population.

In the next section of this Review I introduce literature which may require a paradigmatic shift by the reader in considering the views of two authors from Narrative Medicine and Cultural Studies who have offered a critique of biomedicine's dominance in Western health and social care.

2.8.7 Narrative medicine and cultural studies – a critique

I conclude this section of the critique of biomedicine's approach to MUPS by referring to Dr. Rita Charon, a leading protagonist of the narrative medicine movement (1996), and Dr. Catherine Belling (2012) writing from a cultural studies perspective. Charon has been very forthright about the reasons why doctors and healthcare professionals should embrace narrative concepts, particularly in terms of centring the patient's subjective voice about their experiences of illness.

Charon (2008, p.6) writes candidly about the limitations of the scientific model in her profession and the inflexibility of an 'expert' knowledge when applied rigidly to the patient's experiences of illness.

The patient is isolated by fear of disease and the professional isolated by knowledge of it...healthcare professionals may be knowledgeable about disease but are often ignorant of the abyss at which patients routinely stand. They have no idea most of the time of the depth and the hold of the fear and the rage their illness brings.

Charon's (2006 p.6) primary goal is to persuade others from the medical profession to incorporate narrative sensibilities into their medical practice:

Listening for stories is what we in healthcare must learn to do. To listen to stories we have to know first of all that there are stories being told. We have to notice metaphors, images, and illusions to other stories, genre and mood. What am I trying to convey is the kind of listening that will not only register facts and information but will be reading between the lines of listening and recognise what the teller is revealing about themselves.

Catherine Belling (2012) introduces aspects of post-modern thought whilst continuing to use modernist labels 'hyperchondriacs' in her comprehensive and vivid exploration of hypochondria. From the perspective of this thesis the reader may wish to substitute MUPS for hypochondria, as her critique of the biomedical approach is equally valid for both terminologies:

Hypochondria is not the patient's illness. It is a condition of knowledge that exceeds medicine's classification of health and disease because the content of hypochondria concerns the very capacity to make that classification in the first place.' (Belling, 2012, p.4)

Belling (2012, p.5) understands hypochondria as a 'problem of knowing, telling and anxious imagining in the context of the medical health seeking and risk averting contemporary culture'. She suggests that hypochondria is a condition of medicine which marks the edge of the boundary where medical knowledge is confronted by doubt. Belling (2012) considers hypochondria as medicine's Achilles heel where the vulnerabilities of medicine's positivism is exposed. She suggests that to continue to pathologise the condition is to ignore very real distress, and exposes both patients and physicians to the stresses of irreconcilable conflict.

There are signs that Charon and Belling's critique of biomedicine's limitations in addressing 'ambiguous conditions of doubt' are beginning to bear fruit. It is significant that the term hypochondria has been dropped in DSM-5 (2014). However, the medical profession's research departments and training modules largely remain rooted within positivism which continues to shape the knowledge and practices of healthcare professionals who operate within the profession's

preferred narrative templates. Therefore to embrace the reflexive processes in theory and practices as recommended by the narrative medicine movement is likely to be a slow yet important process.

2.9 Social and Cultural Perspectives on MUPS

I shall now present concepts from social and medical anthropology/sociology in search of ethnographic studies which increase understanding of the cross-cultural experience of MUPS. The literature from these fields of social science focus upon the relationship between body, language and culture. I am interested as to how these perspectives can add to our understanding of the experience of MUPS.

Kleinman, a noted anthropologist has been a protagonist in exploring cross-cultural research on illness. Early in his anthropological work, Kleinman, (1987, p.447) raised four important questions that are relevant for the current study and research in the field of MUPS:

- To what extent do psychiatric disorders differ in different societies?
- Does the tacit model of pathogenicity/pathoplasticity exaggerate the biological aspects of cross-cultural findings and blur their cultural dimensions?
- What is the place of translation in cross-cultural studies?
- Does the standard format for conducting cross-cultural studies in psychiatry create a category fallacy?

I have an interest in what can be learnt from the experience of sufferers across cultures, and to what extent different societal discourses related to illness, disease and medicine bring forth differences and similarities in experience. My theoretical standpoint includes the notion that lessons can be learned in contemporary Western medicine from practices and experiences in cross-cultural and traditional communities and societies.

2.9.1 MUPS – an idiom of distress

Some studies have suggested traditional cultural groups have a paucity of language to describe intra-psychic experiences and express distress in somatic rather than psychological terms, (Leff, 1981). Herman (2007) suggests that the narrative paradigm relies upon structural linguistics. When linguistic competence is absent or lacking what happens to those without linguistic competence? As discussed earlier in this Review many unexplained symptoms (including chronic pain) in common with traumatic events which trigger emotional distress are not easily storied, and subjects may not have access to apposite vocabulary to describe their experiences.

There are multiple explanations from within and outside Western culture that families may use in accounting for their experiences (Berganza, 2003; Bhui and Bhugra, 2002). Proctor and Loader (2000) working in a paediatric setting suggest that trying to apply Western methods to oriental families can increase obstacles to improvement or recovery. Proctor and Loader report that only after these families returned to their country of origin did children recover through traditional medicine.

Kihlstrom and Kihlstrom (1999, p.23), writing in modernist first-order language, identify abnormal illness behaviour as central to the notion of 'self' in health psychology:

The somatoform of disorders are mental illnesses that masquerade as physical illnesses and they are primarily encountered and treated by primary care physicians. As such, they may offer a unique perspective on how people's self concepts and self-images are related to their health and illness behaviour including their reactions with health care professionals.

Other medical anthropologists suggest that developing psychological explanations for physical symptoms is a Western invention and somatisation is closer to the norms of the rest of the world. Thus, cultural factors help determine the extent to which a person uses somatic complaints as a means for emotional communication and social control. For example, Kirkmayer (2007, p.37)

highlights ethnographic research which makes it clear that many culture-bound syndromes are not syndromes but metaphorical descriptions and causal explanations presented in everyday language: 'Cultural idioms of distress are culturally prescribed modes of understanding and narrating health and broader personal and social concerns.'

Helman (1994, p,36) explores the ways different cultures shape their suffering, which supports Kirkmayer's conclusions. In the 'language of distress symptoms mirror the psychosocial conditions of experience and produce a subjectivity that escapes the clutches of reductionist diagnosis.'

Kirmayer, (1986) and Kleinman, (1985) suggest that somatisation arises from the basic processes influencing the social construction of the self, the premise being that people have two means of expressing emotional distress; somatisation or mentalisation. However, I wonder if these designations would be better viewed as two polar positions on a spectrum of experience?

Britt Krause's (1989) study on 'depression' amongst South Asian men living in Luton, goes beyond the psychiatric diagnosis of somatic and conversion disorders, and hypochondrias in the absence of physical diagnosis. Krause has focused upon social and cultural explanatory models in search for alternative understanding of MUPS.

Cruikshank's (1998) work on social stories from the Yukon territories is another good example of an alternative culture that raises epistemological issues about past Western classificatory practice and contemporary theoretical constructions. Yukon storytellers demonstrate the ability to build connections where rifts might otherwise appear, they use narratives to dismantle boundaries rather than erect them, and stories to overcome divisions by 'thickening' the narratives to reframe and provide a broader context in solving divisions or conflict.

Dr. Jaakko Seikkula's team in Finland introduced the practice of 'Open Dialogue' similar to the practices of the Yukon First Nation Elders with positive results with patients who experience first-episode psychosis. The introduction of

dialogical and narrative practices could bring a tangible difference at the interface between MUPS sufferers and healthcare professionals in the initial onset of physical distress and at various points along the young person's journey with MUPS.

The above selection of literature from social and cultural sources reminds us that there are other explanatory languages for MUPS beyond the Western classifications of diseases and syndromes. Some of these cultures would see unexplained illness as an idiom of distress to which non-medicalised forms of healing may be applied.

In these more traditional cultures there may be a number of rituals and ceremonies related to transitions of life and the management of illness and disease. In contemporary Western life there is a reduction of ceremony and ritual involving time and protected space afforded to young people, as the religious, civil, class ceremonies have less influence upon family and community life. I have considered if this may be a contributory factor for some adolescents who may subconsciously express symptoms as a means of 'dropping out' of an increasingly pressured phase of life. I therefore briefly explore a ceremony from anthropology, which has resonances for the way we conceive an adolescent's passage from childhood to adulthood in modern societies.

2.9.2 Transition rites and ceremonies in traditional cultures

The term liminal (rites of transition) was first used in anthropology by Arnold Van Gennep (1909, p.65) in his study of rites of passage. According to Van Gennep rituals:

marked a process of passing through three phases of transformation; the 'rite de separation' when the individual is initially separated from society or social group; the 'rite de marge', the transition stage when the individual has left his former state, but not yet entered his new one; 'rite

d'aggregation', when the newly emerged persona is accorded a new status upon re-entry into the group.

Victor Turner (1967) elaborated upon the phase of liminality, which he explored as ritual, drama and performance in a public way, and defined as a space 'between and betwixt' the normal day-to-day social and cultural life that serves to reverse roles and status.

Miles et al. (1998) have used the term 'liminality' to cover the experience of patients with cancer and chronic illness. The researchers see liminality as a process in the life of illness. The initial onset of illness is typified by disorientation, a sense of apprehension about loss of control and uncertainty. Within the adaptive phase of liminality the patient creates and re-creates meaning by means of narrative. This phase can endure for years or until the end of life.

The authors highlight the significance of the relationship between the changing physical body that houses disease, and the self in meaning-making. In common with the adult patients in this study MUPS sufferers also can experience alienation from 'social familiars, expressed as an inability to communicate the nature of the experience of illness; and a persistent boundedness' (Miles, 1998, p.1485) I understand this to mean that a heightened consciousness of the body due to pain or symptoms raises the subject's awareness of the limits of space, time, and opportunities for empowerment.

The isolation of young people with MUPS from peers and school means they have reduced access to modern less formalised rituals than their peers i.e. attending the school prom or applying for or beginning college or university; contemporary context markers that offer purpose and meaning through periods of social transformations. The experience of MUPS mirrors the liminal space and time described in more traditional societies. The young person's development appears 'frozen' between childhood and adulthood, resulting in a lengthy liminal phase and moratorium from the forward momentum of life.

It was useful to explore the above cultural studies, which led me to consider how in some communities there are no preconditions or classificatory systems to interpret or label mind/body distress. Physical and emotional distress are indivisible.

The Third and final part of this Review introduces concepts from contemporary authors in systemic, dialogical and narrative fields who have presented concepts and narrative themes which have added to the profundity of my research position and approach.

Griffith and Griffith's theoretical approach in their seminal work *The Body Speaks* (1994, p.46) harnessed language and dialogical discourses essential to the understanding of the bodily conditions, 'language events and physiological events constantly select and constrain one another via the body's emotions'.

2.10 Concepts from Systemic Family Psychotherapy and Narrative Research

Griffith and Griffith (1996) grouped traditional models aimed at understanding and treatment of somatic symptoms into four categories; Neuropsychiatric, Psychoanalytic, Cognitive/Behavioural, and Biosocial.

These traditional models it is argued, lay within the modernist period of science and health care and 'attribute little validity to the personal story about a somatoform problem as it arises from the experiences of the patient and family members except to the extent that these meanings fit the assumptions of their theoretical positions.' (Griffith and Griffith, 1996, p.21)

The authors' categories are useful in identifying the different paradigms through which the problem of MUPS is perceived (albeit their practice is with adults). I briefly report each category with some references to what has been added to each field in the last 20 years in Appendix 2.

Griffith and Griffith's (1994) critique of these four paradigms also recognises their contribution to understanding and treating mind-body problems in training programmes, and they have expanded the conceptual thought through which we consider mind-body problems. However, they argue that all four paradigms fall short when it comes to a useable general theory when working therapeutically with somatic problems: The shortcomings of these approaches are identified as follows:

Stories that subjects and families give about their experiences are largely discounted in favour of an expert story defined by professionals. The approaches employ an implicit "bureau of standards" that invests 'standard observers' with the authority to declare what is real and not real about the problems. The particular languages that are used in each of these approaches draws certain aspects of a patient's experience into sharp focus while obscuring others. (Griffith and Griffith, 1994, pp.21-22)

Griffith and Griffith (1994) argue that there is a lack of awareness from clinicians in each orientation about how their preferred language describes mind/body problems. This lack of awareness also means that there is no avenue through which an understanding of a problem can augment the unique language that patients and family bring.

Griffith and Griffith (1994) identify the shortcomings of unilateral approaches and advocate a language-based systemic approach rooted in narrative theory in the treatment of MUPS with adult sufferers. They quote Maurice Merleau-Ponty and Martin Heidegger who spoke 'about metaphors available to us in our language as lanterns that light up an area of a dark forest, each metaphor can only illuminate only an area of our experience, while leaving the rest in darkness' (p.23).

When I first read *The Body Speaks* I was inspired by the Griffith's approach to mind/body/culture problems. I found it inspiring to discover authors from within systemic family therapy who had constructed such a lucid theoretical approach that resonated with my own emerging theoretical and clinical position in relation

to MUPS. The text offered an understanding different from traditional evaluations of mind-body problems: an approach that harnessed language and dialogical practice essential to the understanding of the bodily conditions.

Griffith & Griffith's coherent exposition of the narrative approach to treating unexplained symptoms based upon the premise that MUPS sufferers have suppressed self-narratives which conceal 'unspeakable dilemmas' linked to past or present traumatic events in personal and family life has been an influence upon my therapeutic practice.

Twenty years have passed since the publication of their book and clinicians and researchers from within the four paradigms have continued to make further contributions to the field of MUPS. I am surprised how the overarching approaches within the book to understanding and treating MUPS sufferers have not been more widely incorporated into healthcare practice. I believe it will be important to try to develop an on-going dialogue between the current generation of researchers and clinicians from the different traditions in order to create the best possible context to improve the therapeutic interventions for young people and their families who live with MUPS – and indeed for sufferers across the lifespan. As Harrington (2008, p. 247) has pointed out 'mind/body narratives hang around, because like stories, they are open to multiple interpretations, and this interpretative openness allows diverse people to meet quite different needs from the same stories'.

The way in which this Literature Review has been organised will hopefully assist the reader in appraising what the literature has to contribute in the different research opinions and theoretical perspectives upon the phenomenon of MUPS. I also hope the reader will have a clearer sense of the researcher's theoretical standpoint and focus. In the final part of the Review I explore concepts from my epistemological position.

2.11 Constructing 'Experience' through Relationship, Dialogue and Narrative

Theoretical understandings of the relationship between body, language, self and culture have developed more formally with the development of the movement for Narrative Medicine. The impact of this movement is significant and growing, and yet it remains of relatively limited influence in the face of the growth of biomedicine's dominance in Western health services.

Through the course of researching this review and undertaking fieldwork, I became increasingly confident that applying a dialogical narrative framework to the study of MUPS would allow freedom from the constraints of biomedical and some psychological approaches 'characterised by the process of rationalisation and oversimplification which suppresses the 'voice of the life world and subjective experience in favour of evidence based and tangible pathology' (Bendelow G., 2006, p. 59).

Listening to, and reading the stories of illness and disability I became increasingly aware of the benefits of emphasising the relationship between narrative and experience.

Mette Bech Risor's (2006) study has a focus upon the social construction of illness behaviour as a social process. Risor interviewed adult patients with MUPS at intervals over a two-year period. Her results point to different ways of understanding illness, which include taking into account the processes of developing identities and new strategies for living. She suggests patients with MUPS endure two different kinds of suffering. Firstly, the physical experience causes pain, uncertainty, and distress impacting on family life, finances and psychological well-being. Secondly, the discourses informing practice in primary care (education) and social welfare can lead to suffering, which undermines the construction of identity (Risor, 2006).

The anthropologist Anderson (2001) highlights narrative meaning as a means through which an understanding of the subjective experience of illness can be validated. Anderson believes that a person's engagement with the concept of

narrative is an opportunity for the transformation of the individual's internal stories of pain to dialogical and relational narratives.

Anderson suggests that for an effective narrative transformation to take place access to dialogue and alternative stories from other family members about the illness behaviour and the life experiences of the patient are 'unpacked' to include new reconstructed meanings and interactions.

Initiating a dialogue with MUPS sufferers and their families to include alternative stories about, for example, positive identity, and possibilities for improving relational and emotional well-being, reduce the dominance of the illness story upon the individual sufferers and family life (White and Epston, 1990).

A family narrative approach to the reconstruction of MUPS sufferers' relationship with their condition and illness identity is a very useful and potentially therapeutically productive approach. However, each family can have a distinct set of idiosyncratic circumstances that have led to severe MUPS, which manifests itself in an all-consuming and often prolonged hold of the illness story upon the young person and family members. Family members may have inchoate or broken stories of their experiences. In such circumstances it is unlikely that family dialogue and alternative stories is likely to produce the kind of difference in meanings that Anderson suggests – at least in the short term. Bringing a number of families together at different stages of recovery could facilitate the process of narrative reconstruction.

In terms of how narratives reflect the 'lived experience' of young people and their families living with MUPS, Arthur Frank in his seminal work *The Wounded Storyteller: Body, illness and Ethics* (1995) has developed three narrative types that offer a useful framework for understanding the experience of MUPS.

Frank (2010, p.6) proposes that any unique story of illness is based upon at least three core narratives, which he names 'the restitution narrative, the chaos narrative and the quest narrative'. Narrative types are the most general storyline

that are essential to a plot. People tell their own stories by also drawing upon and combining narrative types that cultures make available.

The restitution narrative has a plot that is based upon someone becoming sick, being treated, and having health restored. The main characters are the medical professionals whose expertise brings about the restitution; the sick person is cast as a passive person 'appropriately called the patient because he or she waits for someone else to do something.' (Frank, 2010, p.118) This narrative type is embedded in the biomedical and modern culture generally.

I imagine that young people's and their parents' experiences reflect most closely the second narrative type, the 'chaos' narrative. Frank (2010, p.118) describes an absence of plot in this narrative type:

because the protagonist is stuck within an immovable complex of obstacles, including untreatable medical problems, financial problems, family problems...The chaos narrative is anti-narrative, because one thing does not lead to another. Everything gets in the face of the ill person, blocking movement toward any kind of meaningful response.

The chaos phase of illness results in distinctive feelings such as uncertainty and a sense of loss of control for sufferers and close family.

The stories people generate within a chaos narrative are often fragmented or broken, leaving them feeling anguish. As Frank (2002, p.102) points out the chaos narrative is often beyond speech: 'Chaos is what can never be told; it is the whole in the telling, chaos is the ultimate muteness that forces speech to go faster and faster, trying to catch suffering in words'.

In the 'quest' narrative the protagonist rediscovers movement (of thought). The ill person is an active character who discovers meaning in illness and his/her situation; illness is not a good thing but people find ways of living with it and keeping a forward momentum to their lives. Frank (2002) concludes that narrative types allow for recognition of individual story, whilst recognizing that

individuals do not construct stories entirely by themselves. An advantage of having access to Frank's illness typologies is that they assist in the naming of the differences and representations between narrative experiences and therefore they have become part of my research lens in the fieldwork and analysis aspects of the research.

An author from a systemic and narrative psychotherapeutic field who has influenced my research position is Glenda Fredman (2004). Fredman introduces us to a theoretical framework that proposes two types of emotional discourse: first, the autonomous discourse, in which emotions are seen as internal, feelings are understood as inside our bodies and emotion is an internal sensation. The second discourse is relational; in which emotions are created between people, they are not bounded, we learn to perform emotions from culture and social situations we are most familiar with.

Fredman (2004) suggests that health professionals and parents caring for a sick child in hospital may perceive the child's emotional distress as connected to disturbed internal emotions, rather than perceiving the triggers for the distress as present fears about a ward environment or a painful treatment.

Freedman's theoretical framework is useful as it could assist MUPS sufferers, parents and healthcare professionals to differentiate between their own feelings and the young person's emotions, at a time when parents and child are more closely bound together due to illness. This close physical proximity in the parent adolescent relationship in a developmental stage, which usually would see less dependency and increasing separation of the young person, can foster both autonomous and relational emotions. In this situation there is potential for mis-attribution between the young person and their parent about which type of emotional discourse is underpinning 'embodied distresses'.

Illness and unexplained illness have straddled the worlds of pre-modern, modern and post-modern society. Bourdieu (2000) theorising against 'misplaced objectivity' has been an influence on anthropological thinking in

relation to bodily practices of everyday life, their replication through culture, and their relationship to discourse.

Bourdieu identified concepts that provide useful frameworks in the study of 'unchosen choices'. People often grow up in stories but some are often 'unchosen' and provide a template for experience. 'People grow to choose stories but they have less choice about the principles of their choosing' (Frank, 2010, p.25). Crucial to Bourdieu's thesis is the concept of a person's 'habitus', which could be described as a disposition or second nature:

Dispositions suggest not what people are determined to feel, want, think or choose, or act to bring into being, but rather how they feel conducted to do what they do; as they undertake their lives, the course of that seems to flow most naturally (Frank, 2010, p 52).

Thus, when unpacking the 'experience' of any individual or group, it seems appropriate also to consider the 'unchosen' or implicit narrative templates that influence thought or behaviour. Bourdieu is interested in the tensions that can emerge in conscious experience when hidden principles become more exposed. He quotes an African woman to highlight the tensions involved in the pre and modernist experience of illness:

In the old days folk didn't know what illness was. They went to bed and they died. It's only nowadays that we have learnt words like liver, lung, stomach, and I don't know what! (Bourdieu, p 34).

The medical historian, Ann Harrington organizes her history of mind-body medicine around five narratives (2008). For Harrington narratives are like rules of grammar that we learn from constant repetition and exposure until dependence on them becomes second nature. Harrington proposes that our ability to tell and understand a story is reliant upon our narrative resources.

Harrington proposes six narrative templates into which most stories of mind-body medicine fit. 'She calls the narrative templates: 'The Power of Suggestion',

'The Body That Speaks', 'The Power of Positive Thinking', 'Broken by Modern Life', 'Healing Ties', and 'Eastwood Journeys'.

Harrington describes her initial rules about what constitutes a story:

a story selects, identifies and affirms the importance of certain values. Stories in any field often draw on more than one template, but the templates are the fundamental narrative resources that set the terms of thinking, acting and even imagining (Frank, 2010, p.123).

Kaethe Weingarten (2001) and her daughter Miranda Worthen (2001) have given us a vivid picture of their very different subjective experiences of illness from the same family. Miranda's story has many features that are common to young people with MUPS. Weingarten contrasts her own disease, breast cancer, with her daughter's, who is diagnosed with a rare genetic disorder. Weingarten believes that the classificatory schemas such as Frank's (2004) have helped her to assimilate the experience of illness, in that they provide specific ways to resist cultural ideas that are embedded in the characteristics of illness and its reaction to society. Weingarten suggests that her own disease, has a 'narrative coherence, closure and independence; and that there is a high cultural resonance associated with the disease that is absent from her daughter's illness which is virtually unknown and has a low cultural resonance' (2001, p.112). In cases of disease with high cultural resonance there is a plot-line informing the actors of the stages of medical treatment, and the patient and family members are given likely situations to expect through the course of treatment and the recovery phase, including the likely emotions that may be triggered such as fear, worry and sadness.

Worthen (2001, p.126) vividly describes her struggle to disassociate herself from an identity dominated by illness:

'Since so many of my health problems were invisible – headaches, dizziness, muscular pain – it was harmful to let other people decide by their

muddy impressions whether or not I was healthy. I wanted to be the only one who was empowered to judge my strength’.

2.12 Conclusion to Literature Review

This exploration of the literature from different disciplines on the subject of MUPS has demanded some awareness of what constitutes ‘experience’ in terms of modernist and post-modern epistemologies.

Auerswald (1987, p.317) has highlighted the tensions for family therapy clinical/researchers situated in the Western world, which ‘remains rooted in Cartesian/Newtonian, 19th century mechanistic and reductionist ‘common sense’ despite the basis for a new non-mechanistic and non-reductionist reality systems that have been emerging in the twentieth century. The juxtaposition of both reality systems...has produced much confusion’.

Since Auerswald’s observation there have been developments in both the empiricist traditions in social science research and in the social constructionist, narrative and dialogical approaches to research, which have sought to introduce subjective accounts into research methods designed to generate understanding through exposure to first hand accounts of people themselves’ (Gergen K., 1999).

I have explored the literature upon the experience of living and working with MUPS to include writers and researchers from both modernist and post-modern traditions. Within a postmodern framework consciousness is brought forth by distinctions in language, which are then experienced by the observers as realities that are independent of one’s cognitive activity or experience of the world. Second-order cyberneticians point out that there are as many ‘realities’ as the observer can create; these distinctions inform how the observer experiences the world.

However, what this broad Literature Review has revealed is a paucity of first-person narratives of young people and their parents/carers, who live with MUPS. This research will begin the process of gathering more stories from MUPS sufferers, parents and professionals who may feel marginalised, frustrated or powerless to improve their circumstances.

Working in a large hospital where the power of modernist biomedical paradigm to label and fixate identities, it can be difficult at times to sustain my preferred post-modern stance. The philosopher Wittgenstein (1980) in his later writing identifies the essence of 'withness', which helped me to be clearer about my research position in the existential world of illness and unexplained illness.

'If the place I want to get to could be reached by way of a ladder, I would give up trying to get there. For the place I have to get to is the place I must be at now. Anything that I might reach by climbing a ladder does not interest me' (1980a, p.7). 'If you want to go down deep need do not travel far; indeed you don't have to leave your immediate surroundings' (1980a, p.50). Where others go ahead, I stay in one place (1980a, p.66)

I now present my Research Question followed by my rationale for the research design, based upon what has been learnt about the phenomenon of MUPS in the review of literature.

2.13 Research Question

What meanings do young people, parents and healthcare professionals attach to their experiences of living and working with MUPS?

The wording of my research question developed over time. I think these changes mirrored a greater clarity about my theoretical standpoint (constructionist, dialogical and narrative) in relation to the investigation into the experience of MUPS. Throughout the research process I have had to reflect upon the notion that 'experience' and 'meaning' are different constructs when viewed through a modernist and post-modern theoretical lens. It has been

important to explore the relationship between phenomenology of subjective experiences and the social and political structures that can shape them. (Mattingly, 2010)

2.13.2 *Research Rationale*

The broad cross-disciplinary Literature Review has revealed that MUPS has been under-researched by both health and family researchers. The Literature Review also revealed a paucity of first-person narratives of young people, parents/carers and families who live with MUPS. The gaps in the literature relating to MUPS reinforced my commitment to applying a constructionist qualitative research approach that recognised that first-person narratives are unique accounts that cannot be broken down, and contain the 'truth' of the speaker.

With this preference for accessing first-hand accounts of MUPS sufferers I have chosen a socio-narratology approach to the study of MUPS, which I believe is close to my epistemological research position. Socio-narratology prefers to 'turn matters of theory over to storytellers...social narratology attends to stories as *actors*, studying what the story does, rather than understanding the story as a portal into the mind of the storyteller' (Frank, 2010 p.13).

This philosophy of listening to and accentuating the subjective voices of children, young people and families' experiences of healthcare is central to the commissioning of healthcare in the U.K. Despite the good intentions of various government policy documents such as the Children's National Framework (DOH 2003) which places children's care at the core of the NHS children's and young peoples' experiences of physical and mental health services have been relatively neglected in research over the last decade.

The cross-disciplinary literature search into MUPS has identified clear shortcomings in biomedical and psycho/social deficit models of assessment and care, which have been shown to be inadequate in understanding the 'lived

experiences' of young people who live with MUPS. It also became apparent in a number of the papers dealing with MUPS there was an absence of self-reflexivity involved in their research practices. Thus in common with some professionals in health and social care clinical practice, little or 'no mention is made of the trained gaze of the clinician in constructing what is seen' (Griffith and Griffith, 1994, p.22).

Some of the studies into MUPS use a modernist language about marginalised clinical populations like MUPS sufferers, supported by biomedical and psychological classificatory manuals of disease and illness. Shotter (2004) calls this way of seeing 'aboutness thinking' which includes 'aboutness' language, and as Von Glaserfeld (1988, p.22) has commented 'one cannot use a language without accepting its ontology'.

In respect of the above shortcomings I believe a constructionist qualitative research study utilising a hermeneutic, dialogical and narrative epistemological approach and methods of gathering and analysing first-person stories will enhance our understanding of MUPS sufferers and their parents' experiences. In the exploration of these accounts it may also be possible to abstract the hidden role that dominant institutional and societal discourses/narrative templates play in shaping the experiences and worldviews of those who suffer with MUPS.

Frank (2011, p.182) reflects upon the 'moral' as well the research benefits of accessing first-person stories for those who suffer with chronic and debilitating illness 'they offer a language-terms of representation – in which disease, pain and often surreal impositions of treatment can be reflected upon, integrated into the life of the sufferer, and shared with others'. If, as in the case of MUPS sufferers, severe symptoms cannot be integrated into life, starting a dialogue or narration about pain or symptoms will assist a young person and parent to see the experience as part of life and identity.

I hoped that my research posture, based on deep listening and open mindedness, would facilitate the processes within the focus groups. I would

attempt to engage the focus groups with a 'witness posture' as identified by Shotter, (2004) a posture which is in tune with an open, spontaneous dialogue between group members.

The Literature Review also revealed that there had been no studies undertaken that had their sources based on the first-hand accounts of family members who live with MUPS, so the inclusion of parents in the focus groups gives emphasis to a systemic relational orientation to this study of MUPS.

The following are some questions arising from the review of literature that have informed my research approach and question:

- *What name would you give to your symptoms?*
- *What stories and meanings do young people and their parents develop about their experience in the absence of legitimisation of their pain and illness by medical professionals?*
- *What are the implications for self-identity of the young person and parents due to the experience of MUPS?*
- *What impact does MUPS have upon personal/professional identity of healthcare staff?*
- *What is the experience of the medical encounter for young people, parents and healthcare professionals?*
- *Do health professionals consider the strengths and limitations of their own epistemological positions when in dialogue with young people and with MUPS?*
- *How do young people, their families and medical professionals experience the medical consultation? Is there a difference between what is heard and what is said?*

- *How do young people and parents perceive the professional language of medicine and psychosocial systems?*
- *What role does language and cultural discourse play in positioning young people, parents and healthcare professionals?*

CHAPTER THREE

3. Methodology – Introduction

In this chapter I present the research design and briefly explain the reasons for the changes made from the original design. I shall outline the philosophical and epistemological influences upon my research theoretical position, and reflect upon the challenges in holding a post-modernist stance during the research process. I aim to demonstrate how ongoing self-reflexivity in the researcher role helped me to sustain positions that questioned any strong beliefs, reactions or positions of certainty in the focus group dialogue and the analysis of data. I outline the research methods used for sampling, and my final choice of analysis.

I chose to use a focus group method in this qualitative research study. The focus group is an underused method in qualitative research, and I considered it has potential for accessing the stories of the often marginalised, socially isolated adolescent MUPS sufferers and their families. My rationale of choosing a focus group method was based on a belief that young people and parents who may have felt 'silenced' or 'unheard' in other medical and educational contexts would take strength and solidarity in bearing witness to each other's accounts of their experiences. My clinical experience also informed me of the dialogical and narrative potential within family and youth group work. However, I was also conscious there could be a risk in staging a group context for young people and parents who have been socially isolated for some time, or encouraging engagement in a hospital clinical context that might have unhappy resonances for the participants.

In terms of the doctors and healthcare professionals' accounts in the literature there have been one or two studies that used individual semi-structured interviews to survey the views of doctors' experiences of MUPS (Wileman et al,

2002; Rosendahl, 2005). On a primary level these accounts came across as literal and linear reports.

My aim with the focus groups with healthcare professionals was to engage participants so they felt sufficiently comfortable to share personal as well as professional stories of working with MUPS sufferers. Some questions that came to mind in relation to healthcare professional roles were: what organisational and professional discourses inform their practice with MUPS sufferers and their families? What kind of training or continuing professional development do they receive in assessing and responding to MUPS sufferers' distress? Whose clinical responsibility is it to assess and manage the care of young people and their families who live with MUPS? What is their view of collaborative MDT working with MUPS sufferers? Whose role is it within the hospital to help MUPS sufferers and their parents to process medical information and language? These were not necessarily questions I formally presented to the focus groups but were held in mind during what I hoped would be spontaneous and productive conversations.

The final choice of a mixed method analysis: of Thematic Analysis (TA) and Dialogical Narrative Analysis (DNA), includes a view about the strengths and limitations of these forms of analysis. A rationale for this choice is that thematic research is a useful method for under-researched experiences, whereas DNA compliments my interest in first-person accounts.

DNA also has a primary commitment to the 'unfinalisability of any story' (Frank, 2010), which is a contrast to the restitutive narrative embedded in medical practice. It also recognises that any individual voice is a dialogue between voices, and that any one voice always comprises multiple voices. Thus, we can analyse the stories of an isolated group of young people and their parents who live with MUPS through a research lens, which presupposes that first-person accounts are open to influence and may include other voices from family history or wider culture. These voices presented by the 'subjective voice' may include historical stories of unresolved illness within the family or implicit discourses from societal institutions that may fundamentally shape the account or

contribute to a 'fixed narrative' in the present about idealisation of medicine to cure all life's ills.

3.1 Qualitative Research

Qualitative approaches encompass a wide range of methodologies allowing a fit with particular research questions. Many qualitative methodologies favour verbal data, given its openness to participant's views. This also reflects the trend towards locating meanings within experience through the exploration of personal perceptions or accounts, (Smith, 1996; Willig, 2001). Qualitative Research largely aims to return to the things themselves, thus avoiding the development of premature concepts and unexamined theories distant from the subject matter they aim to investigate (Willig, 2001).

As indicated within the Literature Review of this study there are a large number of qualitative methodologies, as Denzin and Lincoln (2008, p.5) state:

'Many terms, meanings, interpretations, concepts and assumptions are unique to qualitative enquiry and can make access difficult for those new to the field. The complexity of the field is increased if one factors in the competing paradigms, as well as debates and conflicting perspectives both across and within approaches'.

However, 'There is a belief that we are emerging from a scepticism about qualitative approaches which have been previously viewed as unscientific exploratory and subjective' (Denzin and Lincoln, *ibid*).

A.C. Lyons (2011, p.1) has suggested 'qualitative approaches allow for in-depth, rich explorations of psychological issues in health and illness'. They enable scholars to understand the meaning of individual experiences of living with particular illness or chronic conditions, or coming to terms with having a diagnosis – or, as in the case of MUPS sufferers, living without a formal diagnosis.

Furthermore, theories that posit the centrality of affect, feeling, and emotion in the understanding of health, illness and the body can be investigated using qualitative approaches, such as exploring the experiences of pain/unexplained pain, doctor/patient interactions, adherence to or the impact of medications, and the changes and adjustments in lifestyle (Cromby, 2011).

Chamberlain and Murray (2008, p.391) suggest qualitative approaches facilitate investigations of diverse questions surrounding health and illness by

‘enabling understanding of people’s meanings and experiences of health and illness, by revealing complexities and contradictions in health and illness, by examining and highlighting social processes around health and illness and by promoting change within health related contexts.’

Qualitative studies utilising a narrative approach have gained importance in the study of chronic illness as a means of understanding the attempts of patients to deal with their life situations and the problems with identity that illness can bring forth, particularly when one’s early life is disrupted by illness. Chronic illness alters the relationship between the body, self and surrounding world. (Bury, 1982).

Qualitative researchers have become increasingly aware that illness narratives are constantly influenced by situational factors, which facilitate new stories about the experience of living with symptoms. Thus research can focus upon the different possible narratives which are determined by situational factors and the interaction between the narrator and listener (Clark and Mishler, 1992). For example, a young person with MUPS may offer a different narrative to a doctor or nurse, despite both having a measure of orientation towards the same context – the medical encounter.

3.2 A Social Constructionist and Narrative Orientated Study

Social Constructionist and Narrative concepts will strongly influence my epistemological position. Whilst there are epistemological differences in these

two bodies of theory they share much in common (Flaskas, 2004). These defining features of constructionism clearly resonate with narrative theory and analysis (Potter, 1997; Reissman, 2001). A central theoretical thread, which unites each approach, is the movement away from realism towards multiple truths, which are constantly open to revision through dialogue and wider cultural discourses or stories. Bruner (1991) argues for a theory that recognises that people's experience and behaviour are shaped by intentions, and these intentions are shaped by culture. Bruner (1991) argues for an interactive or cultural theory of mind, rather than the isolated individual mind as epitomised in Western philosophy.

Lincoln and Guba, (1994) suggest that qualitative research situated in the social constructionist paradigm consider research data, such as research participant's accounts as 'constructed' from within a particular research context rather than an objective reflection of reality.

Social Constructionism draws on the idea that everything that is stated is done so from a position and that the same event or experience can be interpreted in many different ways. These ways of knowing are negotiated through social interactions over time and in relation to social structures, contexts and resources that support, or indeed suppress these ways of knowing (Shotter, 1993). A consequence of this way of understanding the constructive role of language is that multiple versions of disease, illness or health may be shared within the same society at the same time (Stephens, 2008).

Gergen (1994) emphasises the social origin of people's perceptions and world-view; an individual's construction of their world is based upon social interaction. The degree to which a given account of the world or self is sustained across time is not dependent on the objective validity of the account, but on the fluctuations of social processes. Truth becomes a question of power, and who is in position to get his or her account verified as representing reality. Social Constructionism acknowledges that the power issues involved in multiple constructions reveals that some versions of knowledge are privileged and some versions of knowledge remain hidden, or are not socially acceptable and

therefore may not be accessible to many. For example, the dominance of biomedical versions of disease and the devaluing of 'lay' versions of illness/health is an example of the way societal discursive practices can work in contemporary Western societies.

Stephens (2008) suggests an example of the material effects of prejudice through discursive practice is demonstrated in the way that Maori health knowledge and practice has been repressed through past legislation and on-going state funding for only Western medical practices.

Narrative theory has generated a growing body of research in relation to illness and its impact upon identity (Bulow & Hyden 2003; Becker, 1997; Brockmeier, 2002; Cain, 1991; Charon & Montello, 2002, Frank, 1995; Good, 1994).

Cheryl Mattingly has highlighted the great potential of narrative in the domain of chronic illness. She raises a central question for MUPS sufferers without probably having this particular group in mind when she observes:

What might it mean to be healed when a cure is only a distant possibility or no possibility at all? The inevitable poverty of biomedical responses to this question is why narrative is so irresistible...stories, told or acted, offer healing possibilities that reach far beyond the purview of biomedicine. (Mattingly, 1998, p.74)

Mattingly believes that stories can transform identities that have become broken, fragmented, closely attached to pain, uncertainty and stigma associated with illness by offering alternative meanings to the past and new images of possibilities for the future.

My research practice will be guided by narrative concepts in terms of the frameworks they offer to 'unpack' meaning, and claims to identity for adolescents with MUPS and their parent/carers, who in the absence of medical and social recognition continue to search for meaning. Equally, narrative and dialogical approaches with their focus upon a subject's story and language are

able to expose oppressive assumptions about a condition like MUPS embedded in the dominant cultural templates of the modernist paradigm.

Bakhtin (1981) devoted a long career to developing the moral ideal of human relationship as dialogue. For Bakhtin (1981, p.287) we are all 'wrapped in another's consciousness'. In the process of dialogue, the words that people use are laden with cultural meanings they have accumulated throughout their lives. Any one speaker invests his/her own personal and situational meaning in dialogue with another. Therefore, embedded in the dialogue between for example, the researcher and focus group participants there can be multiple narratives that contain a complex mix of worldviews embedded within the words.

My discovery of socio-narratology and its practice of Dialogical Narrative Analysis (DNA) (Frank, 2010) opened up the possibility of combining my research interest in narrative theory/analysis with the dialogical, as outlined by Bakhtin: 'Analysis is always about the relationship between at least two and most often three elements: a story, a storyteller and a listener' (1982, p16).

It was following the broad sweep of cross-disciplinary research on MUPS and qualitative methods in health studies and a period of reflection upon the gaps and limitations of this research that I arrived at a Research Design that was closest to my epistemological position, research question and aims.

3.3 Research Design

This was a qualitative research study with data collected from seven focus groups held in the CAMHS Paediatric Liaison Department in a Regional Hospital, in the East Midlands. The first set of focus groups involved two groups for adolescents with MUPS and two groups of parents of adolescents with MUPS. Three other focus groups involved healthcare professionals who work with adolescents and their families with MUPS; two groups of doctors comprised of community and hospital paediatricians, child and adolescent

psychiatrists, and medical trainees. A third focus group was comprised of clinical nurse specialists, physiotherapists and a hospital teacher. The focus group discussions were transcribed and two forms of analysis were used: Thematic Analysis (TA) and Dialogical Narrative Analysis (DNA).

3.3.1 Changes from the original Research Design

There were two changes in the Research Design from the original design. Firstly, I added a third focus group for healthcare professionals. Secondly, the mixed methods of analysis were changed from Discourse Analysis and Narrative Analysis to Thematic Analysis and Dialogical Narrative Analysis. The rationale for these changes is included in the sections under Focus Group Practice and Research Analysis.

3.3.2 Theory and Utility of Focus Groups

Focus groups were originally used in advertising and market research in order to explore the population's reaction to wartime propaganda in the 1920s and 1930s, and as part of public policy and communications research in the U.S. (Krueger, 1994; Morgan, 1988). By the 1970s the focus group had continued to be utilised as an adjunct to the preparation of survey questions and to seek opinions about consumer preferences (Morgan, 1988).

In the last two decades focus groups have gained greater prominence in social science research (Barbour & Kitzinger, 1999; Bloor, Frankland, Thomas and Robson, 2001; Wilkinson, 1999). The same period has witnessed widespread use of the method in qualitative research studies in illness and health (Bullington et al., 2003; Pillittere et al., 2003; Eysenbach & Kohler, 2002).

Focus groups make use of communication between research participants in order to generate data. They are useful for revealing through interaction the

beliefs, attitudes, experiences and feelings of participants, in ways that would not be viable using other methods such as individual interviews (Gibbs, 1997).

Focus groups usually consist of a number of participants who have been selected because they are homogeneous in some respects. Generally the participants are not previously acquainted with one another and therefore do not constitute a 'natural group', although more recent researchers utilise pre-existing groups (Kitzinger, 1994).

Jenny Kitzinger (1994) and Sue Wilkinson (1995) have done a great deal to highlight interaction between group members as a strength of the focus group method. They suggest the role of moderator is crucial as a facilitator at the beginning and end of the group. Groups may develop a special dynamic in which participants are able to discuss, debate and differ over key issues. Kissing, (1996), Stewart and Shamdansani (1990), describe this interactional quality to be superior to one-to-one interviews and ethnographic observation.

Wilkinson (2005) suggests that the reason research utilising the focus group method may have been slow to develop could have been due to issues of data and group management as well as ground rules, which for example dictated that only one person should speak at any one time and that there should be no crosstalk. However, in the last three decades increasing numbers of focus group researchers have championed the method because of the significance of group interaction for producing unexpected insights and meanings over one-to-one interviewing (Morgan, 1997, Kissling, 1996).

In the planning stage of the focus groups I believed that some of the earlier focus group research procedures remained lodged in functional practice with the researcher armed with the interview/question schedule and 'ground rules' for behaviour and participation of group members.

Markova et al. (2003) whilst seeing the potential of focus groups above individual interviews for collecting 'rich verbal interactional data' (p.45) also observed the gaps in focus group procedures, which they believed was lacking

an explicit theory and disregards language and communication. Markova et al. (2003, p. 4) conclude that:

focus group research...needs theoretical models that conceive the group and the individual as complementary...and require methodological tools that account for the shared assumptions, attitudes and knowledge as well as emotional and unconscious alignments in focus groups.

I therefore became interested in developing a second-order approach to expanding the focus group method. This allowed the researcher greater manoeuvrability in their role between centre and peripheral positions within the group; allowing natural voices, interactions and stories to emerge about the topic under discussion.

Systemic family psychotherapy has accumulated concepts that adapt well to focus group research methods. Central to this body of knowledge is the individual in relationship, the concept of the socially constructed self and the importance of dialogue and context (Campbell et al., 1989; Campbell et al., 1994). A number of concepts and techniques from systemic psychotherapy are transferable to the focus group context such as expanding the moderator's role to include the theoretical concepts of curiosity, neutrality, circularity, circular/reflexive questions, self and relational reflexivity, and attention to the emotional postures of the moderator and group participants. The 'use of self' is a particularly useful idea in demonstrating trust and authenticity with research participants of variable ages, genders and cultures.

3.3.3 *Making the most of dialogue and interaction in focus groups*

In order to make more use of focus group data Wilkinson proposes greater attention to group interaction/dialogue in the analytic process to demonstrate 'the common knowledge shared by individuals into shared knowledge elaborated consensually' (Hughes and DuMont, 1993, pp.794-5). As well as giving greater meaning to otherwise marginal values and beliefs, group interaction dialogue is notable for challenge and disagreements between group

participants in constructing the development and elaboration of meaning within accounts.

For the purpose of research into MUPS the interaction/dialogical focus group model is used in preference to the tradition of non-dialogical focus group formats. These two methods could be described as methods of 'proof' or methods of 'invention.' The model of proof reflects much of the early focus research utilising content analysis in the study of communication defined as an objective, systematic and statistical technique enabling the classification of messages or their parts into units (Holsti, 1968).

Despite this growing research interest in group interaction Wilkinson's (1999) and Kitzinger's (1995) reviews of published focus group reports found that focus group data is most commonly presented as if it were one-to-one data, with interactions rarely reported let alone analysed. 'Where interactions between focus groups participants are quoted, they are typically not analyzed at all, or analyzed solely the level of content' (Wilkinson, 1999, p.6).

Focus groups have been successfully employed in health research (Wilkinson, 1999) on women's experience of breast cancer and pain sufferers' experiences of medical encounters (Grace, 1995) or the social representations of health and illness among Chinese people living in the West (Jovchelovitch and Gervais, 1999).

A further rationale for my choice of the focus group method arose out of other researchers' observations about the need for involvement and participation of young people in research. Day et al. (2006) in a study of children's views of mental health care found the use of focus groups was generally a successful method. They found the focus group offered a safe environment with a favourable power differential which allowed the children to explore their views even though they were critical of the service provided. Keeping the focus group relatively small ensured that a theme generated by one child could easily be picked up and explored by the other participants.

Children and adolescents may feel more comfortable in the company of their peers, in preference over one-to-one interviewing. The focus group can facilitate the exploration, expression and clarification of their views (Horner, 2000; Kitzinger, 1995; Sim, 1998).

Given that adolescents with MUPS may have been isolated from their peers for some time, I considered the point made by Day et al. about keeping the group small to be important. Beyond the question of size of group careful consideration was required in terms of researcher engagement and potential for interactional talk between group members.

3.3.4 Sampling

As I am based in a large regional hospital it seemed appropriate to use a strategy of convenience sampling when recruiting to the focus groups. Adolescents and their parents were recruited from the Paediatric Liaison teams and Paediatric Rheumatology's specialist team in Chronic Fatigue Syndrome (CFS/ME). The advantage of this type of sampling was that adolescents attending inpatient and outpatient services were on the more extreme, severe end of the spectrum of MUPS sufferers. It was this cohort group with high levels of severity and longevity of living with MUPS which constituted my main research interest. Furthermore, trips to the hospital were one of the few outside contacts that the adolescents were having, due to lengthy absences from school or college, little contact with friends or involvement in leisure and social activities.

In terms of recruiting healthcare professionals to the focus groups, apart from two consultant community paediatricians, the other 12 were hospital-based clinicians who had some experience of MUPS. Although invited, no G.P.s were able to attend the groups. Those doctors and healthcare professionals who were able to attend, appeared to have an interest in the subject, but had varying degrees of experience in working MUPS patients.

3.3.5 *Recruitment to focus groups*

Parents, young people and healthcare professionals were initially sent a letter, an information sheet, and focus group guidelines (see Appendix 3). Those who did not return the consent/opt-out form within two weeks were contacted by telephone.

When young people, parents and professionals consented to participate I met with them face-to-face or made telephone contact prior to the focus group. This contact gave the consenting adolescent, parent and healthcare professional the opportunity for clarification and to ask questions about the purpose of the group, to share any doubts and uncertainties, and expand understanding of what was being consented to.

The contact provided an opportunity to develop rapport, for the participants to gain a sense of the personal/professional and emotional style of the researcher, explore the potential benefits and risks, carefully attend to the ethical principles of the research, and provide an opportunity to reconsider their participation. Information sheets tailored to the appropriate level of understanding, were prepared for all research participants. All research participants completed and signed/dated the video/audio consent forms for research purposes. Information giving and consent was dynamically integrated into the life of the research project (See Appendix 3). I aimed to act honestly, maintain a transparent and open posture and communicate with group participants in a way that was sensitive to their unique 'otherness'.

This ethical stance is particularly important, as young people and parents who agreed to participate in the study were already vulnerable and in some cases mistrustful of professionals due to their perceptions of experiences in hospital wards or their previous medical encounters. I maintained an awareness throughout the study that some focus group participants may have difficulty in comprehending if the study was not in their interests, or when disclosure may have been damaging to them, due to age, stage of development or other vulnerabilities.

As moderators we were particularly aware of the privacy of participants and this was reflected in the guidelines and process of each group and was emphasized to participants. As moderators we strove to create a warm, encouraging and hospitable atmosphere in the groups.

Group members were made aware they could say as much or as little as they wished, and if for any reason they felt uncomfortable or distressed were aware that they could leave the group or meet with a qualified psychotherapist who was available during and after the meeting.

Issues of confidentiality were discussed with participants including any exceptions to the code of privacy such as if safeguarding issues had been disclosed within the group. Participants were made aware that the study was part of a doctoral thesis, and tutors and supervisors would have access to the data and information gathered. Group members were made aware both in writing and verbally that their identity would be protected by changing names and other identifying features. Group members were informed of the arrangements for storage of data: transcripts and video, and informed about timescales for erasure at the completion of the thesis. Refreshments and travel costs were arranged by the moderators.

3.3.6 Research Participants

	Adolescent Focus Group	Parent Focus Group	Doctor Focus Group	Healthcare Focus Group
<i>GROUP 1</i>	Matthew (18) George (16) Lillian (16)	Martin Carol Kathleen Louise	Dr. D Paediatric Consultant, Primary Care Dr. L Paediatric Consultant, Primary Care Dr. M Consultant Child Psychiatrist Dr. T Trainee Child Psychiatrist	James Teacher, Hospital School Linda Clinical Nurse Specialist Andrea Clinical Nurse Specialist Rebecca Clinical Nurse Specialist
<i>GROUP 2</i>	Julie (17) Matthew (18) Lillian (16) Angela (14)	Carol Martin Dorothy Sue	Dr. D Paediatric Hospital Consultant Dr. H Paediatric Consultant, Rheumatology Dr. C, Dr. J, Dr. G Paediatric Gastroenterologists Dr. I Paediatric Neurologist Dr S, Dr. M Child Psychiatrists	

3.3.7 Focus Group Practice

A colleague from a Paediatric Liaison Service from a neighbouring NHS Trust, Clare Nichol joined me to conduct the focus group interviews and share the moderator role. She is a systemic family psychotherapist and we share a commitment and passion for paediatric liaison work together with a special interest in MUPS. Clare acted primarily in an observer role within the groups but

would occasionally ask a thoughtful question drawn from a stance of curiosity. In this way she was able to provide invaluable feedback to the group and myself about the process and content during the reflective conversation at the end of each group.

3.3.8 The Adolescent Focus Groups

In the planning phase of the focus groups we aimed to create a relaxed and permissive atmosphere. I began each with an overview of the aim of the group and introduced some ground rules.

At the end of each group members and moderators reflected upon the group process and content; with questions, doubts, criticism and anything that could have been done differently to improve the experience.

This close moderator relationship between Clare and myself allowed us to move in and out of the observer positions, which was important for keeping on track, maintaining neutrality and consistency across each focus group. We carefully coordinated our roles and responsibilities during the group and met for half an hour pre and post each focus-group meeting.

In a pre-group discussion prior to the first focus group I had noted some personal professional reflections about the moderator role with the adolescent group. Clare and I both shared our memories of our adolescent years. We pondered how we may have viewed older adults, and what it was we admired or disliked about their styles. We both shared our reluctance to engage with older adults in authority whom we felt had been prone to making judgments despite acknowledging we could both be judgmental during our adolescent years.

These kind of hypothetical discussions proved helpful in centring the adolescent in the heart of the group process, setting a tone and culture of appreciation of attendance, participation and general contributions of the adolescents who participated in the group.

Whilst I felt confident in the choice of method of focus groups. I had two anxieties about the practice one of which was whether I would be able to recruit sufficient numbers of group members to make the research viable. Second, I wondered whether we would be able to establish a safe enough context for research participants, who may have been socially isolated or marginalised from significant institutions for many months, to share their more intimate stories about their experiences between themselves within a relatively short time period.

In considering focus group interviews, Kruegar (2003) recommends a sequence of open-ended questions that avoids dichotomous questions. Questions should be designed to encourage participant involvement including reflection, examples, and choices, rating scales, and drawings. Beginning and ending (summarising) in a focus group is crucial, and at these stages the role of the moderator is central.

Prior to the first adolescent group I followed some of Kruegar's recommendations and laid out a sequence of broad open-ended questions, which I gave as a paper copy to each group member, together with a verbal proviso that the questions were merely a guide and we were happy if the course of the discussion developed in a way that was not in line with the planned questions.

In the first focus group, the adolescents appeared to engage well with the process and to offer their accounts about their experiences of living with MUPS. However, I felt an implicit expectation from group members that I lead the discussion through questions and prompts. I also had some anxiety, which may have reinforced this 'conductor role', about sufficient 'difference' within the group discussion, coupled with a worry that the conversation would come to a halt without my interventions. I frequently found myself offering short prompts such as 'How do you see this?' or 'Does anyone have a different view about this?', with the intention of keeping the dialogue moving.

Indeed, there was certainly less confidence shown by the adolescents to disagree or build upon each others' accounts directly, but they did share their respective stories of their experience of living with MUPS, listened with interest and carefully to each other, and appeared to non verbally endorse each other's account.

In the second focus group I did not produce a list of questions and decided to offer open questions/prompts spontaneously. This group had two new members and two members from the first group. Good engagement was important and staying welcoming but neutral without referring to any great extent to the relationships built in the first group was necessary. Again, the group appeared to engage well, and there was a similar pattern of participation by the adolescents: with limited verbal interaction about topics, but plenty of non-verbal utterances (such as laughter) between group members.

The main difference for ourselves as moderators in the second focus group was that we felt freer to move from central to more peripheral positions as the group members' confidence increased. As a consequence of this change towards less structure, more spontaneity emerged within the group process and this new stance in the moderator roles was carried through into the rest of the focus groups.

This freedom of movement of the moderator between the centre and periphery (Cruz and Pereira, 2007) of the groups' dynamics allowed us to monitor the balance between quieter and more vocal members of the group to share their views, seek clarification or occasionally ask questions designed to evoke different perspectives about the topics under discussion.

At the end of each group the adolescents were invited to share their opinions about the group. Following the conclusion of both groups they commented that they had enjoyed the experience; that it had made them feel less alone with their difficulties and that they found it helpful to know there were others who shared similar experiences.

3.3.9 *The Parent Focus Groups*

In contrast to the adolescent groups the communication within the parents groups was more fluid and group directed. I was able to ask fewer questions and the need for prompts was less (Hyden & Bulow, 2003), with the aim of allowing a natural discourse based upon group members' 'conception of their experiences' to emerge (Friere, 1998). As moderators we also felt more comfortable tolerating slightly longer 'silences' within the parent group, and were able to allow longer pauses, in the confidence that the 'silences' would be broken by the interjection of a group member rather than by ourselves.

As moderators we both felt that each person in the parental focus group had really felt a need to tell their story and to use the opportunity that the focus group offered them for ventilating feelings associated with their experiences. In nearly all instances, each speaker would respectfully take turns without researcher prompts, and embark upon very lengthy and sometimes monological stories. In the post-group reflection discussion between the moderators we considered why the parents may have used this style of telling. It was agreed that for the parents it may have been their first opportunity to articulate their experiences: having their accounts connoted by others with a shared understanding of each story in a non-judgmental atmosphere may, it was agreed, have been the explanation for the propensity towards the 'monologue' style of discourse by some parents.

The parents therefore used the opportunity of the focus group 'as a narrative portal; desiring to get their versions of events across and attaching their subjective experience to their account' (Bamberg, 1996, p.335).

To assist participants to feel relaxed and engaged with the moderators and the process it was important that we were able to use clear, concise language when introducing the aims and basic rules to group participants. In the adolescent groups we introduced an ice-breaking exercise, which required a small amount of self-disclosure and 'playfulness' by group members and ourselves. In the introduction it was important to convey to all group members that their views

were appreciated and valued, and similarly that we displayed an informality, transparency, authenticity in our verbal and non-verbal interactions with group members.

In prefacing the aims, purpose and guidelines for all groups we aimed to maintain an open physical posture and a non-condescending tone. I kept any instructions short and to the point. In 'warming the context' for each group we aimed to connect with each person as a unique individual and for who they are. Throughout the focus groups we were both aware of processes in the group that may silence or undermine a group member, but that in guiding the balance of 'voices' within a group discussion the more vocal and reserved participant should both be carefully attended to and recognised for their respective contributions of speaking and listening.

At the end of the focus group interviews with adolescents I requested feedback about the group process. Most participants suggested that they had felt comfortable because there had been some prior non-research talk with the interviewers. Group members said they felt more at ease because the interviewer has stressed 'there were no right or wrong answers' and other participants were respectful and listened to each other. Some group members also mentioned that they had agreed to participate in the research as it could be beneficial to others who shared a similar plight to themselves.

3.3.10 Doctors' and Healthcare Professionals' Focus Groups

I decided to host separate focus groups for doctors and healthcare professionals. I made this decision on the basis that the medical hierarchy in the hospital may have resulted in the healthcare professional deferring to the doctors in the group discussion. However, I was also aware that by not mixing the group I may have narrowed the diversity of opinion in the groups.

I considered the healthcare professionals' group would be a useful addition, serving to broaden the healthcare 'experience' of MUPS beyond the daily

medical practice arena of consulting rooms and ward round. The healthcare professional specialist role gives more opportunity for time and accessibility with MUPS patients. This level of contact means that adolescents and parents may be more disposed to approaching them to seek clarification, share feelings and dilemmas about the absence of a diagnosis, treatment and on-going illness experiences. Similarly, it is also more likely that healthcare professionals bear witness to the emotional impact of MUPS on the young person, family life and relationships. The healthcare group was composed of clinical nurse specialists, hospital teachers and physiotherapists whose contact with MUPS sufferers is either face-to-face or/and by telephone/email contact.

3.3.11 Some Limitations of Focus Groups

A limitation of the focus group method is that the expression of group norms may silence an individual voice of dissent or difference (Kitzinger, 1995). The presence of other respondents may compromise the confidentiality of the research session. The moderator can have less control over the data produced than in a one-to-one interview. As the focus group method is increasingly used in research with socially marginalised vulnerable groups there may be less diversity of views arising from group discussions as participants search for solidarity with the dominant core values about their experiences. (I raise more issues about the focus groups in the Discussion Chapter.)

3.4 Researcher Reflexivity

My personal experiences in childhood included severe scalding as an infant, enuresis and a number of epileptic episodes in middle childhood and early adolescence, leading me to consider the significance of memory and relationship in the context of child and adolescent illness. I became aware of how family and cultural responses to illness can shape our ways of processing and managing illness. Reflexivity with my own stories of illness in childhood and adolescence and in my role as parent and grandparent, assisted me in

attending to helpful/unhelpful pre-understandings that could potentially enhance or hinder the research process (Burck, 1995). These personal experiences, combined with a number of years of clinical experience with child and adolescent illness, have increased my sensibilities to ethical and unethical practices in researching the intimate views and feelings of vulnerable adolescents and their families.

I found it difficult to access a vocabulary to describe the fear and anxiety of an epileptic seizure. These fears – probably combined with seeing the anxiety in my parents' faces – provided the ingredients for a silence between us about what was happening, leaving us internally managing these occasional calamitous events individually.

The experience of illness as only partially told, or un-storied in the dialogical sense, and of how individual family members can become isolated, managing the emotional impact and sense-making of illness through internal conversation alone, are two key connections that I shared with MUPS sufferers in the study.

I have utilised a combination of these personal and professional reflections with illness during various stages and processes during the course of the research. However, I have also heard the cautions of Ethrington (2003), who suggests that researcher reflexivity is open to many interpretations and there are risks and benefits in including the personal 'voice' in writing or presentation in the research process. He cautions against the researcher's 'signature' being written too strongly or too thinly when analysing participants' stories.

I have come to appreciate that reflexivity within the researcher role is a question of balance, in order to avoid either too much subjectivity or too much objectivity. Stepping back within the research interview or analytic reading to locate my own views, feelings and pre-understandings in the face of feedback from participants allowed me moments to consider the stories that others bring to the research process and greater freedom to explore the multiple contexts which inform participants and my own actions and practices (Fredman, 2013).

In order to maintain effective reflexivity throughout the research process I kept a research diary and memos after each focus group. I sought supervision in the fieldwork and analytic phase of the research from doctoral supervisors and peer researchers. I shared my interpretations of stories (and utilised feedback) from the focus group material with my co-moderator, Clare, research supervisors and a research colleague in my workplace. A senior colleague read my analysis of the transcripts at various intervals to check for ethical language and interpretation.

Researcher reflexivity added validity and rigour to the research process. This entailed making explicit the processes in the researcher/participant relationship: maintaining an awareness of issues of power and scrutinising my own beliefs, positions, and pre-understandings with a level of diligence in the reading and analysis of participants' accounts.

3.5 Transcribing

The focus groups were both video and audio taped. I transcribed five of the focus groups and two groups were transcribed by a colleague. Transcribing the seven focus groups took longer than I expected, but the advantages outweigh the expense in time and energy, in that I got a good sense of the material and the dialogical processes between the speaker and the listeners. I primarily drew upon transcribing conventions of Jefferson notation (Appendix 4) which represents analogic aspects of communication as well as digital.

As all participants were respectful of each other and there was very little cross-talk, apart from jokes or utterances implying agreement with a storyteller's point, I was able to capture most of the verbal talk. The video-taping of sessions proved to be invaluable for transcription purposes as some of the audio tape recordings were inaudible, particularly when several people were speaking simultaneously. Other benefits of video recording were that I was able to capture emotionality within and between research participants. Every effort was made to transcribe all recorded speech.

3.6 Ethical Issues

I received ethical approval from the Nottinghamshire Research Ethics Committee (NREC) in January 2008 (see Appendix 5).

Holloway and Jefferson (2001) considering the ethical dilemmas in healthcare research suggest that four principles associated with bioethics are worth recalling – beneficence (doing well); non-maleficence (not doing harm); autonomy (people's right to choose); and justice (fair and equitable treatment for all).

The increase in qualitative studies employing psycho-social perspectives over the last two decades and utilising biographical and narrative methods with subjects from marginalized groups has highlighted that aspects of the four bioethical principles appear inadequate.

Holloway and Jefferson (2001) suggest that 'the avoidance of harm' could be interpreted as the avoidance of emotional distress. Yet psychosocial approaches challenge the belief that it is best to avoid emotional distress. 'According to this model it is not necessarily harmful if research raises painful and distressing experiences, though it may be discomforting' (p.98).

The inclusion of emotional, social, cultural and political dimensions in research data is a way of capturing the many 'truths' of lived experiences in health research (Murray et al., 2004). In fact, the subjective experiences of distress in the domain of MUPS can often be constructed out of the conflict in discourses between the individual sufferer and the physician.

Holloway and Jefferson have developed three additional principles. Honesty; approaching the data openly and even-handedly in the spirit of enquiry not advocacy, only making such judgments as could be supported by a authentic reading of the data and not ignoring data. Sympathy; or the capacity to enter into the feeling or sharing the feelings of others: 'We put ourselves alongside them attempting to use what self knowledge we possessed and the difficulties

we were familiar with, to assist us to understand their inconsistencies, confusions and anxieties' (1998, p.406). Respect; to pay attention to, to observe carefully.

Kotze et al. (2012) has coined the terms 'prescriptive' and 'participatory' ethics. Prescriptive ethics is based upon 'a process of deductive reasoning grounded in systems of 'truth' that are mostly embedded in scientific and/or religious discourses. This form of ethics has objective or transcendent status and is not bound by time or context, thus assuming prescriptive status' (Kotze et al., p.12).

This kind of prescriptive truth will have been a dominant discourse in both pre-modern (religious) and modernist societies (Science/Medicine). Under prescriptive ethics there have been exemplars of where marginalised groups have suffered, ignored or labelled i.e. see the Bristol Royal Hospital for Children Inquiry.

Participatory ethics requires an ethical consciousness situated in the participation of all, especially those who are usually marginalised or silenced.

Ngwane (1994, p.118) clarifies the praxis of participatory ethics as 'not a set of systemic standards for the judgment of rightful behaviour. It is a form of rightful behaviour, it is a form of praxis, life and commitment...The presence of the poor (or marginalized) is a mocking counter gaze to any ecclesial notion of wholeness'.

Kotze et al. (2012) sees narrative as a meaningful way to present and procure ethical ways of being participatory manner. Sevenhuijsen (1998, p.29) supports the practice of ethics 'as a narrative and textual practice. Moral stories about care can be seen as a means of interpretation and communication, in which people from a diversity of positions and perspectives exchange values and aims relating to care'.

I actively engaged in the values of participatory ethics throughout the course of the research study. Group members shared their stories of illness and disclosed

intimate details associated with the essence of their existence. I actively took steps to treat this raw data in a discreet and careful manner, during the process of coding, classifying and interpreting, and ultimately preparing representation to others.

My main goal as a focus group moderator was to support the adolescents, parents and healthcare professionals in full participation in the research process, and to feel they could express things freely in their own language and terms of reference.

Focus group members were made aware that they could withdraw from the study at anytime. The researcher ensured that no harm would come to individuals or their future treatment hampered if they decided to withdraw, and that questions and comments about the content and process would be welcome both during and at the end of each focus group.

I ensured participation of the adolescents and parents in the research study would not affect their medical/therapeutic care. All adolescent and parent focus group members were offered post-research debriefing/therapeutic support from a psychotherapy colleague in the Paediatric Liaison Department. In terms of doctors and healthcare professionals I arranged for a healthcare professional from a neighbouring Healthcare Trust to offer time for debriefing or therapeutic support if required. However, no group members took the opportunity to debrief following the groups.

Qualitative methodologists agree that the ethical issue is not simply attaining the respondent's consent to have his or her story recorded and analysed. There has been less discussion about what constitutes respect for stories in narrative analysis.

I received supervision from a mentor with experience working in the field of MUPS and in qualitative research methodology, in order to maintain a balanced professional response to ethical dilemmas as they arose through the course of the study.

On the completion of the report I invited the group participants to a presentation of the research. I also prepared a summary of the research for each group members and welcomed criticism and feedback.

3.7 Rationale for choosing Thematic Analysis and Dialogical Narrative Analysis

In this part of the Chapter I shall offer a rationale for a mixed method of analysis of focus group data and the change in the Research Design from a Discourse/Narrative analysis to a Thematic/Dialogical Narrative Analysis.

The purpose of disciplined qualitative approaches to analysis is to describe and to explain the essence of experience and meaning in participant's lives (Denzin and Lincoln, 2003).

I chose to use mixed method of analysis to the focus group data. The most common way of analysing focus group data is through content/or thematic analysis (Wilkinson, 2003a). The two are not always clearly differentiated, but content analysis may sometimes include quantification and thematic analysis may include extensive quotation of the data. Wilkinson (2005) is surprised how little attention has been paid to these interactional processes in focus group analysis. In her view, focus group data has been presented as if it were one-to-one interview with interactions between participants rarely reported. If they are alluded to, it is at the level of content or description rather than interaction.

Another form of meaning construction frequently identified in qualitative data is story (Mishler, 1986). The underlying premise of narrative theory is the belief that individuals live most effectively by storying their experience (Bruner, 1991; Riessman, 1993; Wiltshire, 1995.) Narrative theory (Bruner, 1986; Ricoeur, 1985; Labov, 1997) has become increasingly used in clinical practice and research in the fields of bioethics and the medical humanities (Launer, 2002; Shapiro, 2004).

Narrative is the paradigmatic mode for sharing experience, and is based upon the premises that human beings think narratively and construct stories to make sense of chaos and give meaning to existence (Bruner, 2002) The narrative paradigm can offer a form of enquiry that goes beyond dualistic explanations and brings our attention to what is explicit and what might be hidden in narratives in ways that might not always be comprehended by those constructing them.

3.8 Thematic Analysis

Thematic analysis has less of a profile than other forms of analysis in qualitative research i.e. grounded theory or narrative analysis, despite being a widely used analytic method (see Boyatzis, 1998; Roulston, 2001) in social science research.

Braun and Clarke (2006) describe thematic analysis as:

‘a method for identifying, analysing, and reporting patterns (themes) within data. It minimally organises and describes a data set in (rich) detail. However, it also often goes further than this, and interprets various aspects of the research topic (Boyatzis, 1998, p.2).

Thematic Analysis is a useful method when investigating an under-researched areas, as is the case with MUPS sufferers and their parents. (Braun and Clarke, 2006).

What counts as a theme?

According to Braun and Clarke (2006) a theme captures something important about the data in relation to the research question and is representative of a patterned response or meaning within the data set. An important question to

address in terms of coding is what counts as a pattern/theme and what 'size' does a theme need to be?

Ideally, a number of themes will emerge across the data set, but the number of occurrences do not necessarily mean the theme itself is more crucial than a theme in a single-data item. There is no definitive answer to the question of what proportion of the data set needs to display evidence of the theme for it to be considered a theme (Braun and Clark, 2006).

Themes or patterns within data can be identified in two ways in thematic analysis: in an inductive approach (Frith & Gleeson, 2004) or a deductive approach (Boyatzis, 1998; Hayes, 1997). An inductive approach means the themes identified are strongly linked to the data themselves (Patton, 1990). In this approach, if the data has been collected specifically for the research, i.e. via interview or focus group/s, the themes identified may bear little relationship to the specific questions that were asked of the participants. They would also not be driven by the researcher's theoretical interest in the area or topic.

Inductive analysis is therefore a process of coding the data without trying to fit it into a pre-existing coding frame. However, if priority is given to an inductive approach there is also an element of deductive appraisal required on the part of the researcher. This method is also favoured by Bauer (2000), who argues against a purely inductive approach, stating that codes should also be derived from existing theory.

Braun and Clarke (2006) emphasise the need to retain flexibility in the application of thematic analysis. It was important that I kept an open mind when determining what constituted a theme, rather than selecting codes or themes simply on the basis that they fitted with my theoretical pre-understandings. Furthermore, the significance of a theme is not necessarily dependent on quantifiable measures, but rather in terms of whether it captures something important in relation to the overall research question.

3.8 Thematic Analysis in Practice

I closely followed Braun and Clarke's (2006) guide for undertaking thematic analysis. Following initial readings of the entire dataset I concluded that the reader would benefit from conveying a sense of the important themes in the material that would be based upon the inductive method. However, I also included an element of deductive appraisal generated from my theoretical and epistemological position, based upon an awareness that 'data can never be coded in an epistemological vacuum' (Braun and Clarke, p.12).

I began the analysis by noticing patterns of meaning and issues of potential interest during the data collection. I read and re-read each transcript of the focus group interviews to identify sections of text (coding units) that were potentially of interest. Codes identify a feature of the data (semantic content) that appears of interest to the analyst, and refer to 'the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon' (Boyatzis, 1998; p. 63).

I worked systematically through the entire dataset, giving full and equal attention to each data item. I then identified interesting aspects in the data items that I considered formed the basis of repeated patterns (themes) across the datasets from all the focus group interviews. Coding was undertaken manually and was largely 'data-driven' with the emerging themes dependent upon a combination of the data and the processing of the material. Each coding unit was coded exclusively into just one category rather than into multiple categories.

Joffe and Yardley (2004), suggest this allows very clearly defined coding categories to be developed, which enhances the development of the theoretical basis for the coding decisions. I coded for as many potential themes/patterns as possible. A long list of codes emerged from the reading/re-reading of each set of data codes. I then worked back and forth within the data, to consider the relationship between codes, between themes, and between different levels of themes (for example overarching themes and sub-themes within them). I

selected some initial codes to form main themes, other formed sub-themes and some were discarded.

The candidate themes, sub-themes, main themes and discarded codes were then reviewed again. During the reviewing phase it became evident that some candidate themes were not really themes as there was not enough data to support them, or two sub themes could combine to form a main theme. Other themes needed to be broken down into separate themes.

3.9 Narrative Analysis

Narrative analysis is informed by narrative theory, which holds that we create ourselves through narrative, (Crossley, 2000) and that a recursive relationship exists between life and narrative through constant interlinking of experiences and stories. Bamberg (2010, p.3) states that narrative

provides a portal into two realms. Firstly the realm of experience, where speakers lay out how they as individuals experience certain events and confer their subjective meaning onto these experiences. Secondly the realm of narrative means (or devices) that are put to use in order to make (this) sense.

In embracing narrative theory and analysis both as a clinician and researcher working in the domain of chronic unexplained illness I am frequently reminded of the above tension in listening to the broken narratives of research participants and clients.

Mattingly (2000) utilises the term 'emplotment' (a term originally used by Paul Ricoeur) to describe what groups do when they force a preferred narrative on experience. The usefulness of this term is exemplified in Mattingly's research with occupational therapists. She writes 'a plot gives unity to an otherwise meaningless succession of one thing after another' (2000, p.46) and

understands meaninglessness as 'when lived experience seems to be driven by no other form than brute experience' .

'Brute experience' may be seen as an appropriate description of a teenage suffering with MUPS and their parents as they arrive for their 10th consultation with yet another a specialist paediatrician in search of a cause or cure for idiopathic pain that more than likely cannot be provided by bio-medical practices.

It was a combination of the influence of narrative concepts like those above and feedback from the focus group process that reaffirmed my final choice of analysis.

In my original Research Design I had proposed a mixed method analysis of the focus group material of discourse and narrative analysis. I believed that these forms of analysis were close to my constructionist narrative theoretical position. As I explained earlier in this Chapter the focus groups had been less overtly dialogical than I had originally expected. Through the close reading of the focus groups' text I came to the realisation that most of the research participants were using the group format to speak about their stories of living and working with MUPS. The inclination to tell their story was possibly facilitated by the listening and witnessing of other group members who had shared common experiences, thus most of the group members used the group to confirm their stories of MUPS. I gained a sense that group members were seeking solidarity from other group members about their 'troubling' and 'troubled' stories.

The philosophy and principles of Dialogical Narrative Analysis (DNA) (Frank, 2012, 2010, 2002) were in coherence with my moral and theoretical research position. The association between story and dialogue in DNA convinced me that it should form part of a mixed approach to analysis. In identifying the dialogical narrative themes from family and culture that contributed to the shaping of experience of MUPS sufferers and their families DNA would enable me to explore the implicit and absent meanings within the accounts.

I therefore became committed to a mixed thematic and dialogical narrative analysis of the focus group material. I envisaged that the thematic analysis would be a method with a focus upon 'what was spoken about' in the stories of MUPS sufferers' experiences. I believed the outcomes of the thematic analysis would be of interest to readers whose worldviews are drawn from realist rather than constructionist paradigms.

3.9.1 *Dialogical narrative analysis (DNA)*

The main protagonist behind the theory and practice of DNA is Arthur W. Frank, Professor of Sociology at the University of Calgary. There are a number of references to Frank's work on narrative themes associated with living with chronic illness in the Literature Review. Frank's concepts also developed out of his own experience of chronic and acute illness which he wrote about in his book entitled *At the Will of the Body: Reflections on Illness*. His writings have been crucial to my understanding and application of my research approach. I understood that only by immersing myself in Frank's substantial body of work, would I gain sufficient understanding of the theory and practice of DNA to apply it to the large amount of material I had collected from the focus groups.

Frank (2010) also believes it is important that the researcher has a good understanding of the philosophy and practice of DNA. He suggests the researcher should have a clear rationale for the choice of this form of narrative analysis. I have discovered much to inspire in Frank's book *Letting Stories Breathe: A Socio-Narratology* (2010, p.146) and one sentence particularly resonated in terms of my research with MUPS sufferers:

DNA is not exclusively about people holding their own, but the stakes on what stories do are highest when storytellers are working their hardest to sustain their dignity and sense of life's coherence against forces to which they are vulnerable.

The sentence brought to mind the significant efforts of adolescents and parents with MUPS who strive to hold their own coherence of individual and family identities in the face of 'forces' which included the withdrawal of medical and social recognition. A problem for young people and their parents then is that when too much is at stake it can lead to 'reacting quickly to what happens and feeling invested in what happens. Some time is then required to imagine the scene from alternative perspectives' (Frank, 2012, p.39).

DNA utilises and builds upon the idea of representations of subjective truths in research participants' accounts, but there are also notable differences to other varieties of narrative analysis, some of which are related to the dialogical propositions within the approach. DNA is one of a number of variations of narrative analysis (Holstein and Gubrium, 2012). One significant feature that distinguishes it from other forms of analysis is the fusion between narrative, dialogue and relationship.

Frank (2012, p.16) clarifies his reasons for this synthesis:

My version of narrative analysis is qualified as dialogical as a reminder that analysis is always about relationship between at least two and most often three elements: a story, a storyteller and listener(s). None of these could be what it is without the others. What is analyzed is how each allows the others to be.

3.9.2 The principles and practice of dialogical narrative analysis (DNA)

In common with some other varieties of narrative and discourse analytic approaches there is no single method of approach or written procedure that one can systematically follow in DNA and as a novice researcher I needed to learn how to apply DNA to the focus group material.

Frank (2010) is a master of synthesising a number of philosophical and theoretical concepts into this relatively new approach. I immersed myself in the

crucial concepts of DNA abstracted from the dialogical and narrative approaches for it to begin to inform the selection and analysis for the final written report.

Frank's philosophical and analytical approach is well suited to a research study on medically unexplained symptoms because he is especially concerned with stories that 'resist telling'. The nature of the teller's experiences in many of the exemplars he writes about are broken or incomplete narratives in that they do not and cannot coalesce into a cohesive whole.

As a clinician/researcher with a number of years of practice in the field of MUPS I came to understand the importance of careful pacing when "unpacking" hidden or broken narratives in relation to the link between physical and other possible sources of a MUPS sufferer's distress.

In common with discourse analysis there is no clear method or guidelines I could sequentially follow in undertaking DNA. Riessman (1993) suggests that if a method is understood as a prescribed set of steps that the analysis should follow, 'students looking for a set of rules will be disappointed'. Although this is slightly daunting to hear as a novice researcher I gradually began to relate to a sense of freedom and anticipation in facing the task of representation of the focus group accounts.

Frank suggests (2010) that DNA is underpinned by three working principles:

1. *Non-finalisability:*

Frank is profoundly influenced by Mikhail Bakhtin's critique of Fyodor Dostoevsky's novels and sees in Bakhtin's interpretation of the Russian novelist's stories an approach to literature that can be adapted by modern social scientists to the analysis of research interview data.

For Bakhtin (1984, p.193), dialogue implies:

an openness to the difference of the other, also respecting the need to sustain the difference or assimilate or finalise it...to finalise is to claim the last word, especially about who another person can be, finalisation terminates dialogue and leaves the finalised person with nothing more than the finalised state he or she is.

The above quotation led me to me to consider the potential for the power in balance in the doctor/patient relationship.

2. *Second person address:*

Frank (2010), draws strongly upon Bakhtin (1984) 'who suggests the author speaks not about a character but with him'. These premises also echo the work of Shotter et al. (2008) quoted in the rationale for the study who have argued for an ethical and linguistic understanding based upon a dialogical (witness) rather than a monological (aboutness) approach in social and psychotherapeutic contexts.

3. *A Researcher should claim no privilege of interpretative authority:*

Here Frank (2010) again following Bakhtin, highlights the dangers of over-interpretation by a researcher, which can lead to 'finalising' the character in the story or claiming a permanence of coherence or unity from within the story when in dialogical terms it can only be temporary.

Frank (2012, p.33) has highlighted four crucial features when undertaking an dialogical narrative which I have utilised in my analytic practice:

- *'What multiple voices can be heard in any single speaker's voice; how do these voices merge, and when do they contest each other?*
- *What makes stories distinct from other forms of narration; what counts as a story, and what does not?*

- *Why is someone choosing to tell a story, among other expressive possibilities? What particular capacities of stories does the storyteller seek to utilise?*
- *What stakes does the storyteller have riding on telling this story, at this time, to these listeners? How is the storyteller holding his or her own in the act of storytelling? By holding one's own, I mean seeking to sustain the value of one's self or identity in response to whatever threatens to diminish that self or identity.'*

Frank (2012) emphasises that stories should remain whole and that methods that fragment stories should be used for other purposes. However, this posed an immediate dilemma in this study, as many stories of MUPS sufferers may be inchoate and fragmented. I remained mindful that some coherent stories generated from within biomedicine, psychology and psychotherapy can add to professional or cultural ideological theory but from the subject's perspective remain remote from their 'lived experience'. Where longer-term severe illnesses are concerned (Kirmayer, 2000) suggests fragmentary stories or narrative strands may be more revealing than a finely wrought narrative.

Thus a challenge in applying DNA has been to give the reader a sense of the whole as much as possible from briefer extracts, while highlighting narrative or story trails which I considered of some significance and connection to my research question, aims and standpoint.

It is a convention in DNA that a final written report will only contain a few of the original collection of stories for discussion. Most qualitative methodologies would suggest a systematic method for presenting the stories and making accountable decisions for the choice of story for the report, whilst DNA selects stories on the basis of phronesis. According to Frank (2012, p.43) 'phronesis' is a practical wisdom gained through the analytic experience and relies upon:

The analysts cultivated capacity to hear from the total collection of stories, those that call out as needing to be written about, phronesis is practised – it

is a craft not a procedure – it is an iterative process of hearing stories speak to the original research interest, then representing those stories in writing, revising story selections as the writing develops its arguments, and revising the writing as those stories require.

Frank (2010 pp.105-109) identifies six themes in which to guide DNA practice. For the benefit of the reader new to this approach I present an abbreviated version of these themes below:

1. 'Translate the story into images – a first step in interpretation of the work of going into the story is to imagine pictures from a text. The point is not to connect these images; the point is to let them connect, translating the story into images is only a beginning.
2. Translate the story to tell it from a point of view of a previously marginal character. By translating the story into different points of view any unity that the story displays as a narrative becomes understandable as a provisional achievement, not a reflection of reality as it is and must be, but creative act of story and storyteller working together. Dialogical interpretation requires making the achievement of the story questionable in order to ask what that achievement achieved.
3. Notice which details might have been expected but are omitted. Attention to omissions reminds us that stories, more than other forms of narrative, make silence significant. What happens is not the only thing to attend to: what does not happen can be equally worthy of interpretation. To notice what is omitted the easiest role is to tell the story as a performance, asking what every performance storyteller needs to ask.
4. Attend to differences between the storyteller and the analysis.' [Frank repeatedly points out that without difference there can be no dialogue. Narrative analysis may often be inclined to emphasise what the researchers share with participants: interpretation finds a better beginning in identifying difference in participant's stories.]

5. 'Slow down, try not to rush the analysis. Try to listen and wait for things to emerge. If the researcher finds himself/herself stuck with the interpretive work the advice is preferably to go for a walk.
6. Appreciate the story and the storyteller. Interpretation proceeding with dialogical commitments always begins best with appreciation in a broader sense; appreciation for the story that is told and appreciation for what makes that story not only tenable but necessary to tell.

I have concluded that DNA is as much a philosophical and ethical approach to research as it is a practice. Therefore a careful and sincere approach to the analysis of texts is required. In the practice of analysis I have drawn upon different narrative templates, which I found useful as I developed a relationship with the details of the stories being told.

My initial approach to the analysis, really began in the process of transcribing, with an open mind and to make brief notes of words, phrases, nonverbal responses etc which triggered thoughts ideas in me. It was only over time that I recognised that the material triggered theoretical notions from narrative templates which included Frank's (1995) classificatory schema of illness narratives; restitution, chaos and quest typologies. (An explanation of this framework is given in the Literature Review, Chapter 2, and Gonçalves Gonçalves and Ribeiro's (2012) work on the problematic self-narrative as a component of the dialogue in the therapeutic conversation. Gonçalves and Ribeiro identify 'Innovative Moment' (IM) within a person's story or dialogue. An IM has two main features: the presence of a contrast between a previous self-narrative and a new emergent one; and the access to the process, which allowed for the transformation from the former to the last (see Appendix 4 for further explanation of this model).

In Chapter Four I present the outcome of the thematic analysis.

CHAPTER FOUR

4. The Thematic Analysis of Focus Group Transcripts

I have organised the presentation of the thematic analysis by listing the main themes in four tables. A table will be presented at the beginning of each section of the Chapter and includes a list of main themes from the respective research participant groups: young people, parents, doctors, and healthcare professionals. Beneath each table there is a continuation of the discussion of each main theme, illustrated by brief excerpts from participant accounts and the analysis. Sub-themes are included in Appendix 6.

4.1 Young Person's Focus Groups

Table 1: Summary of Main Themes

Memories of times past and pain and suffering in the present:

Young people recalled their former healthy and socially active lifestyles. Comparing this to their current circumstances generated feelings of loss, shock, frustration, anger and sometimes envy of 'healthy' friends and siblings.

Young people's experiences of the initial medical consultations:

Anger and frustration with some doctors and other authority figures; teachers, school attendance officers, siblings, friends, who do not believe explanations of symptoms and suggest other reasons to explain the young people's experience

A critique of diagnosis by exclusion:

Frustration at not having a diagnosis. The impact of 'not knowing' about a cause for the symptoms and treatment to alleviate pain, seizures etc. Focus upon symptoms sometimes becomes all-consuming; to the exclusion of other life activities.

Absence from school and college – loss of confidence in learning and social interaction in school environment:

Worries about being forgotten by teachers and responses from peers about symptoms. Loss of confidence in learning and anxieties about falling behind in work. Having to adjust the timescale and possibilities for academic and career plans.

Sceptical feelings about referrals to psychiatry/psychology.

Limited or no discussion with the doctor about reasons for referral to mental health services or what this would entail with the doctor, leaving the young person with negative thoughts about their state of mind.

The impact of MUPS and illness stories on family life:

Family life and relationships are subject to a lot of change; marked reduction in family activities and perception by the young person that they are treated as a younger child by parents. Experiences of other family members' illnesses from the past can organise family dynamics and parenting of the young person with MUPS .

The impact of social isolation and loss upon identity

Young people isolated from school and interaction in family and social life. The cutting off from external life and dialogues had repercussions for their internal self and thoughts, which were often consumed by loss of confidence, difficulty in seeing a purpose to things, self-doubt, and anxiety.

How to explain 'unexplained' symptoms to family members and peers :

Dilemma's about explaining to significant others an undiagnosed condition and the illness experience generally. Apprehensions about responses from others.

Memories of times past and pain and suffering in the present

Six of the seven participants experienced onset of symptoms in early to middle adolescence, a seventh had experienced severe stomach pain since the age of two. There was a cross section of unexplained symptoms including head and stomach pain, fatigue, non-epileptic seizures and paralysis of limbs.

The adolescent onset group shared their experiences relating to the profound effect of the symptoms upon their previously active lifestyles:

'Um yes, it certainly made a sharp difference to me as I was an ice skater before I got ill I was active and liked walking up hills and mountains and those sort of things but it made a sharp difference as obviously not being able to walk and to do physical things that knocked me back quite a lot.'
(Matthew)

The young person with paralysis in an arm and leg recalled that symptoms emerged over a few days and they had been entrenched for about a year:

'I gave up dancing and stopped attending school in the middle of my A-Levels.' (Julie)

Evoking memories of past times when the young people often excelled in their respective physical activities and hobbies, may have left them with unsettling feelings of loss, frustration or even envy. Such emotions could be triggered in MUPS sufferers by seeing 'healthy friends' continuing to enjoy and achieve in their chosen sport or hobby. This may have been another reason for the self-imposed 'distancing' from friends which some participants later describe in their accounts. Some young people spoke about their initial efforts to maintain their physical activities but gave up these efforts due to the symptoms undermining their efforts to reach their former high standards.

The memories of their active lives were starkly contrasted with their current isolated and lonely experiences at home, without social activity or schooling for long periods:

'...um well I got the kind of feeling of worn out kind of pains and muscles and stuff like that and headaches but I didn't really have much else, it was more of the emotional thing about it and I went really depressed about everything, it was just like, what is the point I thought my friends would just go and I would be left alone and it would be there for the rest of my life, just in bed and just not bothering and then I went really angry (.).' (George)

Matthew similarly recalls:

'The pain didn't bother me that much; I have had something for as long as I can remember so it was the movement; loss of being able to do things as well...as me, that I think was the worst since (3) I remember the point – just burning out really was the reaction – I remember sort of just um, nothing there really, just not really emotions one way or another, just this kind of flat numbness, sitting still and not doing anything, can't get up, can't do much, don't do much – sort of existing really, not much else for as long as I can remember.'

The above two accounts of the impact of pain seem to support the research of Gillian Bendolow (2006) with adults, in which more elaborated accounts of pain appear to transcend the dualistic assumptions inherent in Western medicine and responses to pain are as much emotional and existential as they are physical.

However, Angela the young person experiencing pain from the age of two, could not recall a time when the pain did not feature. Her stories in the focus group were often focussed on pain. However, there are hints in her account that she made attempts to establish an identity socially despite pain at points during her long journey with illness:

When asked by the researcher about how the pain affected her Angela stated:

'I do not think my problem was about confidence, but physical pain. The thing that really knocked my confidence was when I was about 12 I was getting a few hours of pain (3)...It's not really affected me recently because I was in pain.'

Angela's experience of pain as 'all consuming' resonates with the first-hand accounts of adults with chronic illness (Mason, 2004; Biro D, 2010; Greenberg L, 2009; Heshusius L, 2009.) in terms of how pain can destroy most things apart from itself. Contrary to the adult's accounts, I suspect that for Angela her emerging sense of self is in flux and she desires an identity that can transcend others' perception of her 'self' as dominated by pain.

'When I was younger I kind of had friends (.) they were gothic (.) I started dressing like them.... "Oh my god she's such a Goth" when I changed the way I dressed.' (Angela)

Young people's experiences of the initial medical consultations

For all of these participants in the young person's group initial medical consultations felt unsatisfactory and often very frustrating. The young people's accounts emphasised the experience of 'not being believed' or making assumptions that symptoms are psychological or part of avoidance behaviour by doctors, teachers and other medical and educational professionals. The inferences by doctors that it could be a 'mental' or 'psychological' problem evoked strong negative reactions from young people.

'My G.P. was incredibly unhelpful as she said it's "psychosomatic, it is all in your head".' (Matthew)

George and Angela told of similar experiences:

'One of the doctors said there was nothing wrong with me and said that I was just wasting time, you're just lazy... People thought I was mental, just lying about things, which was really unhelpful.' (George)

'I suppose they thought I was so young: they always talked to my parents because I was young, but I don't think they thought I had my own opinions.'
(Angela)

Angela's last point, that she was ignored by doctors who spoke mainly to parents because she was a child, was a common experience among the other focus group members who were all in their adolescence. The young people found the medical encounter a negative experience and that doctors' thought they knew best'. Some doctors left the young people feeling they had been labelled as 'frauds' and were making up the symptoms rather than feeling the doctor had understood their distress or circumstances. These accounts echo Carel and Kidd's (2014) of 'epistemic injustice' in young people's experience of the medical encounter.

A critique of diagnosis by exclusion

The young people's response to the medical consultations resulted in loss of confidence and credibility, feeling that they might be 'crazy' or trying to figure things out themselves by searching for the aetiology of their symptoms on the internet.

The young people were down-hearted because they had expectations that doctors would be experts who would cure them, and they expressed a breach of trust with medical professionals or other authority figures who expressed doubt about their experiences both explicitly and implicitly.

For the young people who were later to receive diagnosis of CFS/ME there was some appreciation of the doctors, who had finally diagnosed their symptoms.

Lillian expressed the view that doctors, 'Tell you what it isn't, but nobody tells you what it is', a phrase I had heard many times from young people and their parents in my clinical work. It highlights the limits of diagnosis by exclusion when applied to MUPS sufferers. The young people in the focus group believed they would benefit from a diagnosis and were not reassured by the absence of disease following tests.

Researcher: *Would a diagnosis have made a difference to your experience of illness?*

Lillian: *You mean an explanation? I don't know, I think it would have been the same but kinda feel a weight would have been lifted, because I always wonder what has been the cause,*

Matthew also stated:

'There's no sense of closure until you find out what it is... The first doctor's appointment I had that really made a difference was when Dr. B called me up ...he must have been studying [my] out-patient records (.) he just said, "Look we haven't explained this yet, can I have a look and try and figure out what it is...." In the end (.) he said they were running me for all the things like MS or Guillane-Barry. I think I suggested ME to him and he said "yeah possibly".'

It is of interest that Matthew raised the possibility of CFS/ME first, which is not a condition you can be tested for. However, the late diagnosis gave Matthew a sense of purpose and 'direction'; 'something to fight against'; which he viewed as preferable to life without a diagnosis which often left him struggling to give meaning to his experience of symptoms. However, despite the diagnosis, the symptoms continued to be managed in primarily non-medical ways.

Sceptical feelings about referral to psychiatry/psychology

Referrals to psychosocial departments were initially met with some scepticism and apprehension, perhaps because inadequate explanations, (in the use of language, which implicitly reinforced stigma) were given to young people or their parents by referrers. Thus, when they attended psychiatry and psychology clinics they were unsure why they were there. The uncertainty about these services changed for most young people following their engagement with services.

‘Initially I felt very weird when I could not understand why I was having physical symptoms I should be referred to a mental health unit.’ (Lillian)

Once young people were engaged with CAMHS PLS there was an appreciation that the activity involved listening, talking and sharing feelings. Some young people expressed concerns about being labelled ‘mad’ if they attended child and adolescent psychiatry. Two young people in the group considered the timing of the referral to a psychological service was important, but would have preferred to have been referred after a physical diagnosis had been given. Diagnosis as a legitimisation of experience gave license to share experiences with a therapist. Other young people in the group stated they continued to find it difficult to benefit from ‘talking’ therapy:

‘I find it hard, I just prefer to just shove everything to the back of my brain to get on with everything normally.’ (Julie)

Another participant with longstanding unexplained stomach pain gave some indication of ambivalence about counselling/therapy in a contradictory statement:

‘I really, really, do not mind talking about it but [then] again it is one of those things I don’t really care to share with anyone.’ (Angela)

Absence from school – loss of confidence in learning and social interaction in school environment

Five of the young people who attended the focus groups had missed large amounts of time at school due to illness and one older adolescent was home tutored after two years in primary school.

'Things got a lot worse in Year 4, I wasn't in school a lot and then I went to my first secondary school. I went there for about seven weeks and then I had to take a year off.' (Angela)

'I had quite a lot of time off school [and] I thought my friends would just forget about me, but when I went back I realised they hadn't and [they] asked about how things were going. I think at first one of my teachers thought I was faking it and other people probably thought the same, but they soon realised that was I under the hospital so they apologised to me.' (Lillian)

Young people who attended school part-time shared concerns about their previous absences from studies resulting in worries about falling behind with academic work and fears they would be forgotten by their teachers and ignored or pressured by peers to explain their symptoms and absences.

The worries that Lillian had about re-engaging with her school initially had some foundation, as a teacher and pupils expressed some scepticism about the symptoms. 'Being under the hospital' gave her an explanation that appeared to convince people that her illness was authentic. Angela stated that her pain got worse in primary school and subsequently has been absent for most of her secondary education.

On returning to school after periods of illness several young people stated they did not like or want the attention that illness brought saying 'I've just been ill' or simple things like, 'I'm fine' in an attempt to deter other pupils' questions or curiosity. Lillian, the young person with non-epileptic seizures tried to explain her condition in ways that would help others see the difference between her identity and the illness. However, this was not straightforward because the

episodes were unpredictable and often involved fainting in public places followed by fairly long periods of jerking and erratic bodily spasms.

'First I was at school quite a lot and young people in my class were staring at me and stuff like that. I was trying to put the point across that it is still me and there is nothing really changed about me... my teachers treated me differently and I said to my teacher "don't treat me differently because you feel sorry for me". I was halfway through secondary school and they treated me differently because they felt sorry for me. They did not know how to treat me.' (Lillian)

In common with a number of other participant accounts, Lillian's preference was not to be treated differently at school, home or socially. Unfortunately, Lillian's largely unconscious episodes were very public and drew attention to her body, which invited reactions of fear or sympathy and defied Lillian's conscious wishes to be treated as a healthy child.

Two young people expressed concerns that there may be stigma attached to illness or disability when applying for higher education. They wanted to be accepted to university on merit and on an equal basis with their peers.

The impact of MUPS and family stories of illness on family life

In the main, young people felt supported by their parents, siblings and extended family from the onset of illness. In the main it was the young people's mothers (in consultation with partners or grandparents) who were the first to assess the symptoms and make the decision to go and see a G.P.

'I think my Mum really was the main person. She understood what I was going through and supported me more than my father or brother. Mum said to my dad there was something not right, so I came to the hospital to see if there was anything that could be done about it... I think it also brought my family closer together.' (Lillian)

The support and advocacy by a parent(s) was common to all the young people in the group who described their parents as pro-active in seeking further medical advice, a clear diagnosis and effective treatment in their communications with medical professionals. Similarly parents took a significant role in negotiating and securing educational input for their children. Lillian's point about the family being brought closer together had a hint of irritation about the increased surveillance, when she added that '...people in my family [were] constantly asking if I was okay'.

Some of the young people said that a parent who had experienced illness themselves had the most understanding of their experience; a mother who had 'viral problems when younger' and two fathers had chronic illness. Two young people disclosed powerful stories about close family members when describing how they approach others with illness.

'My uncle had what I had as a baby. He passed away when I was a year [old] but then like he kind of understood me, because I did not really know about his illness, but then he had a son called M who kind of got this cyst on his appendix and I kind of treated him not differently because he was in a lot more pain than me and because he could not do many things at all. He just kind of sat there going through all of the pain so I kind of tip-toed around him more than I should have.' (Angela)

'My dad understands most since he has MS; its one and the same really.'
(Matthew)

Such powerful stories from the past as Hoptof, (2000) and Hardwick, (2003) have suggested result in family relationships and parenting styles becoming organised around managing MUPS in their child in the present.

There was a consensus amongst focus group members that parents were supportive and sometimes 'nagging' regarding treatment routines and medicines. Their accounts highlighted parents' heightened sense of safety and

protection towards their teenagers who had not relinquished the desire for independent thought and living.

'My mum is still really careful, she is so cautious, she asks how are you feeling? Are you in pain? Are you really OK?' (Angela)

Angela's physical pain led to some fundamental adjustments including serious operations and changing expensive holiday plans:

'Before they took my appendix out they was like you haven't got anything (3) go away it's a stomach thing, then like finally when I was about to die they were like "You've got appendicitis and peritonitis that's why we're taking it out..." It stopped me from doing a lot of things like when I was eight years old my dad took me and my brother to Greece. I was there only for a few days, and had to fly home as three of [the] four days I was in pain.'

Two male members of the group found their family members supportive in the sense that they were able to know when to intervene and when to leave the young people alone.

The impact of social isolation and loss upon identity

Hall-Lande et al. (2007), in a general study of social isolation upon psychological health testified to increased vulnerability to depression, and this appears to be borne out by the testaments of young people in the focus group research. The dislocation from relationships at school and social activities led to a loss of confidence in interpersonal communication generally. All group members suffered social isolation reflected in comments about confusion and self-doubt.

Some group members said feelings of loss of mental capacities such as concentration and memory were a greater loss than physical capacities such as being able to dance or ice-skate. Loss of physical wellbeing however, triggered

different kinds of emotional responses and metaphors that raised questions about solely autonomous mind/body associations in sustaining identity in socially isolated circumstances.

‘...um, well I got the kind of feeling of worn out; kind of pains and muscles and stuff like that and headaches...I went really depressed about everything. I thought what is the point my friends would just go and I would be left alone for the rest of my life.’ (George)

‘...sitting still and not doing anything, can’t get up, can’t do much sort of existing really not much else for as long as I can remember I have ached for something or other.’ (Matthew)

In the above extracts I get a sense of the emotional distress young people experience when at their lowest ebb. There is recognition of what is lost in terms of their physical capacities and fears over loss of their social life. In the first extract Matthew expresses an absence of meaning in life altogether and is living a ‘brute’ experience (Mattingly, 2008). I imagine these experiences are reminiscent of a liminal state (Turner, 1968) or a ‘moratorium’ in adolescence (as described by Marcia, 1967; Erikson, 1950). For young people the combination of social isolation, loss of meaningful external dialogue and MUPS constitutes a substantial threat to self-identity.

How to explain to ‘unexplained’ symptoms to family members and peers

How to explain often complex medical, psychiatric, or unexplained symptoms to school friends, wider family and social circle or inquisitive people was a challenge for all the young people who attended the focus groups.

Julie, the young person who had received a diagnosis of conversion disorder, struggled to explain this condition to family and friends. However, given the very visual impact of her condition she found it very difficult to explain to her peers why her leg was paralysed and twisted, and why she required a

wheelchair. Even if Julie was aware of a diagnosis of conversion disorder it remains an extraordinarily difficult concept to describe.

'I came back to school and young people asked me "what's wrong?" and asked me "why?" and I don't always know how to explain it (.)...I don't know how to explain really, and I found it hard to go back to school because people kept asking me questions and I didn't really want to talk. I didn't really have a lot of information to give people who were asking me questions or to say what it was, it felt a bit strange.' (Julie)

Similarly Matthew highlights the dilemma in explaining to others about the illness and suggests that if he discloses the details of his symptoms to others he runs the risk of being perceived as a sick patient (illness) rather than a person with a distinct identity: 'I do not mind offering the basic explanation, if people know exactly what it is people could then turn you into illness.'

Lillian and George, who offered explanations to peers about their conditions, gave differing accounts of their experiences:

'Yeah because in school my friends were asking what it felt like to be having one, and didn't know why I was having them and stuff like that, but I didn't mind explaining because if it happens around them they would probably feel more comfortable about knowing.' (Lillian)

'I told some of my friends some of the stuff, but I never told them everything 'Eh up, how you feeling' "I'm fine" when I might not have been...keeps them happy; keeps them away from me...I will deal with not feeling fine on my own.' (George)

Lillian has a sense of the possible impact of the episodes on others, facilitating her willingness to give an explanation. George, however, responds defensively to deflect his peers' curiosity and cover up his feelings. This suggests he has had experiences which have made it difficult for him to trust his school peers in the past.

I will explore the Sub-theme of the young people dealing with problems themselves in the Dialogical Narrative Analysis.

4.1.1 Parents' Focus Groups

Table 2: The Main Themes

‘The doctors did not believe our child or ourselves; this isn’t supposed to happen’:

Parents expressed anger and frustration about the initial primary care consultations with their G.P. and subsequent medical appointments. They felt they were not listened to and that their opinions were ignored or disbelieved, echoing the experiences of their child. This is also regarded as a disappointment, as most parents previously had an expectation that doctors’ medical knowledge and experience would produce an explanation for symptoms. Some parents said they felt judged by some doctors and healthcare professionals whom they believed attributed labels such as ‘fussy parent’.

Increased closeness between parent/s and adolescent at a family life cycle stage of individuation and separation:

In common with a diagnosed chronic illness the experience of MUPS draws parents and their teenage children physically and emotionally closer together at a stage of development noted for individuation and family separation. Parenting styles regress in response to the symptoms parents witness in their child. Aspects of parenting are synonymous with parenting a younger child.

Public advocacy and certainty – private ambivalence and doubts:

Publically, parents stated they acted as advocates for their adolescent across multiple contexts. Privately, parents experienced ambivalence and self-doubt about their adolescent’s situation, in their thoughts and conversations at home.

Parental sacrifices as MUPS takes over family life:

Parents told of making sacrifices and putting life ‘on hold’ due to their

adolescent's illness. MUPS, in common with chronic illness, can absorb parental mental and emotional energy with a cost to self and other significant relationships.

The doctors did not believe our child or ourselves; this isn't supposed to happen

An overarching theme in parental accounts was the challenge they and their children experienced when they felt they were not being believed in initial consultations with medical professionals, teachers and their representatives. There were also concerns about a different kind of labelling of their child and themselves by doctors in the initial consultation, which is then perpetuated through written comments in the medical notes.

Parents frequently referred to their intimate and expansive knowledge of their child's experience of symptoms often in a direct comparison to doctors, whom they perceived as dismissive of the accounts of their child's symptoms.

'As a family I would say the biggest thing was the people who didn't believe him, didn't believe us, and just having to close down and say "no" and then you get labelled a "fussy parent"...I noticed "fussy parent" on his file.'
(Dorothy)

We kept taking him, he got stomach pain at the time and the doctor kept saying it was stress which, I mean you know Michael, you can never imagine Michael suffering from stress...he is so laid back he is horizontal, he is a completely non-stressed child – always was.' (Kathleen)

Parental experiences of mistrust and frustration with medical professionals dominated a number of parental accounts. Doctors not believing, or offering alternative opinions about a psychological or emotional cause for symptoms only served to further undermine parental beliefs that doctors are medical experts who assess and treat health problems.

'I think we are programmed to trust the medical profession to a certain extent; these [are] people who studied for many years and they know, and you trust them to look after you. You should go there with a set of symptoms and they say, "Yes it is this, and this is what we do to solve it".'
(Dorothy)

For a number of parents frustrations may be increased throughout their experience with medical professionals on the care pathways from G.P. to hospital specialist consultations. Such frustrations may be linked to the failure to find a clear answer to the suffering of their child, but also disappointment with each consultation or set of investigations, if inconclusive, resulting in the end of yet another medical relationship which may initially have offered expectation and hope of a cure.

When speaking about hospital appointments Clare stated:

'You go along and you have the tests and they say no, its not this and its not that, and then its bye-bye and its back to square one again. You are then referred to another specialist...you are always getting knocked back... rather than being able to go with a specialist who will say "Yes I am concerned about your daughter as well: we will go with you and we'll find out what it is".'

A father pointed out his frustrations with the discontinuity of medical information and communications between medical and allied professionals, which result in the young person and parents frequently having to give multiple historical accounts of symptom on-set and on-going developments.

'When you see somebody else they've got the notes, but haven't read them'. (Michael)

In this sense the parents of young people with MUPS share an experience of illness without end and, echoing the views of their offspring, it appears that most

initial visits to the doctors have an unsatisfactory outcome. An impasse or incongruence in the initial medical encounter sets a tone and defensive posture for future parent and physician relationships.

Increased closeness between parent and adolescent at a family life cycle stage of increasing individuation and separation

In common with parents with a diagnosed chronic, acute or life-threatening illness parent/s (parents focus group participants were predominantly the mothers of young people with MUPS) and children/young people are drawn much closer together due in part to the impact of MUPS. From the parental perspective protecting your child from pain or suffering is as natural as keeping a child fed and warm. This closeness can be in both physical and bodily proximity, and often involves a greater emotional intensity sometimes to the exclusion of other family members.

'It's like going back to having a toddler again...I don't think its been totally negative. Me and Becky are really quite close now um, (.) and I think she's not the same person that she would have been obviously if she'd not been through all this, but then she doesn't have any of that...teenage tantrums or none of that and in some ways it would be nice if she did [laughter]...we have tried to do more things together, you end up with more time with your child than perhaps you would have done with a child who perhaps would be sailing off out at times and you don't know where they are.' (Clare)

For Clare, her daughter Becky regresses in terms of her desire for physical care and reassurance, and yet she shows an absence of teenage tantrums, which suggests the impact of MUPS suspends upheavals associated with transitions in family life such as in the adolescent phase (Carter and McGoldrick, 2005).

The notion of Becky as a 'good child' is also consistent with Kozłowska, et al. (2003) epithet for young people with conversion disorder. In this team's study the symptoms and family relationships were useful sources of developing

meaning for the unexplained symptoms. The closer emotional ties with usually one parent, and withdrawal from active social life reinforces solidarity and exclusivity in the parent/child relationship.

Carol, the mother of a 15 year-old with late diagnosis of CFS/ME spoke about the close physical and emotional proximity she had with her adolescent:

'When she's really poorly I put her into bed with me...she had seven months with me when she did not have a diagnosis, and the psychologist said that's not good for her, so I put her back in her own bed, but I then ended up getting no sleep and was shattered at work, so she ended back in my bed.'

In the extracts below Carol and Martin, who demonstrated solidarity in their views in most of the focus group discussion, describe an increasing exclusivity in the mother/child relationship due to illness, which was a reversal of the previous closeness of father and daughter relationship.

Carol described that before the onset of Becky's symptoms she had been "a Daddy's girl", as she played football in a team managed by her father. Their accounts suggested that the bond with her mother had intensified, while her relationship with her father had become more distant.

'She confides everything in you [speaking to Carol (mother)]. I get home from work and say, 'How are you, alright, any problems?' [She says:] "I've already told Mum I don't want to tell you all over again", so I get it all second and third-hand.' (Martin)

Minuchin (1978), may have described this change in dynamics (primarily in Western families) as due to the illness orchestrating a 'family dance', with increased permeability in boundaries between the marital system and child sub-system than in normal times. These kind of changes in family life, for whatever reason will be unbalancing to family life if the situation persists over lengthy periods.

Public advocacy and certainty – private ambivalence and doubts

Frank (2010) writing from a narrative perspective reflects upon the dilemmas in performing stories of personal experience in what he calls 'narrative authenticity'. If I understand his point correctly he believes there is a precarious relationship between stories as expressions of authenticity and stories as works of witness and advocacy. The stories of advocacy can become deviations from the authentic original experience.

Perhaps this charge of deviation from the original account of their adolescent's experience of symptoms could be attributed to parents in their advocacy role. However, it is important to take into consideration the influence upon parents of the institutional contexts they are dealing with, and the strong emotional ties they will have with their vulnerable adolescent child.

In the parental focus group examples of parents advocating on behalf of their child are multifarious, spanning medical, educational, family and social contexts. For parents, the advocacy role becomes essential and at times they can present as defence lawyers arguing for their client's innocence and integrity. This is particularly evident in the interactions with the young person's school, and with educational professionals.

In describing relationships with both educational and medical professionals parent focus group members used the metaphors of 'battle' or 'fight' when describing their parental positions. The advocacy role develops into parents taking up adversarial positions if professionals are seen to be unsympathetic, dismissive, or challenging in respect of the experiences of the young person or family.

In the absence of a clear diagnosis parents often turn to medical professionals for support to explain their child's on-going absence from school, but are disappointed with the response. Kathleen illustrated this when she said:

'He said to me "I'm a failure because I can't manage to go to school", then he tries to convince the school he's in pain...he says, "I'm scared of school". He's very self conscious, he diagnoses himself you know, but it is very hard because you're not only fighting to find out what's wrong with them, you're fighting all the other things like the system; the same thing with the doctors. We went to the first doctor about the stomach pain, who told us to come back in three months, [and/to] see how he is.'

Louise shared her disappointment with the doctors about the lack of support over the impact of MUPS on her child's schooling:

'We need some kind of medical consultant support at that time to give some sort of diagnosis...I got most angry when I couldn't get any support from anybody in the medical profession, as nobody was willing to say "Yes we recognise you just need a diagnosis, you need time out". They weren't supportive at all about that and it wasn't long after we decided to home educate her.'

Dorothy spoke of her struggles and fears in her attempts to gain recognition of her son's problems and about her sense of being labelled as an over protective parent. In this excerpt there is an implication that parents maintain a holistic view of their child's illness in an era when medical specialisms don't always take the bigger picture into account.

'When they are young they can't do it themselves; you have to do it for them. Getting the medical professionals to listen to parents I think is a huge problem.' (Dorothy)

Carol and her husband Martin presented as a couple who were most strident in their advocacy in medical and educational contexts on behalf of their 15 year-old daughter who has suffered with symptoms from middle childhood:

'We've had big problems with Andrea at school: they've not believed her; not been supportive; only worried about her attendance. I've been to the M.P. and governors, this poor girl has actually been wandering around school in pain and she's allowed to come home in pain, but then there is a report system as she has to walk half way across the school campus to sign out when she can hardly stand up, and I have to ring and say can you do this and can you do that, because you don't seem to understand.'
(Carol)

In Carol and Martin's determination to secure the best care for Andrea some observers may have described their presentation as reminiscent of alexithymia. Lumley et al. (1996) findings implicated disturbed family functioning and maternal alexithymia (externally-oriented thinking rather than reflection on inner experience (Sifneos, 1969) in the development of similar features in children. What these studies tend to ignore is the embedded role of restricted language of professionals representing implicit and explicit discourses in medical and educational institutions. Carol and Martin may be responding in the same restricted language and postures of those representing the institution when advocating on behalf of their child.

Arising from the focus group discussions there was evidence of parental feelings of ambivalence, self-doubt and emotionality combined with capacity for reflection about their child's situation. Such thoughts and postures of parents were limited to the private domain of home and were in sharp contrast to their presentation in the public domain, in which the advocacy role shapes a different kind of narrative and postures about the issues at stake.

When parents and the young person were in an advocacy role it appeared important that all family members have homogeneous views and family solidarity about the young person's symptoms. Family unity is important in their struggle for understanding and recognition with outside institutions. However, some parents offered glimpses of their internal struggles/dilemmas within the family to adjust and understand their child's illness.

In the following two extracts Louise a parent of a 15 year-old with many years of living with MUPS before a diagnosis of CFS/ME, shares her ambivalence and guilt as a parent about how to respond to her daughter's symptoms. Kathleen, mother to 14 year-old Michael, described the impact on the family dynamic adjusting to the young person's symptoms.

'I think it does knock your confidence as a parent because it throws you into that two minds all the time...you don't know what's the best thing for your child: whether to send them to school; whether to keep them off; whether you are doing enough trying to find someone to help them; and you start to feel very guilty...when I look back probably even more guilty...very early on perhaps I neglected her or did I do enough to try and find somebody or should I have pushed her at that point and its constant questions in your mind about whether you're doing the right thing or should I have done something different.' (Louise)

Kathleen continued:

'...and it's the same with Michael; I imagine it is the brain, or is it nerves? He is sensitive, maybe it is something that sets it off? Say you've had a bad experience or something and you've been ill, then the brain remembers that sort of thing but nobody believed him, especially my husband. First of all it was trying to convince everyone in the house that he was in pain, because from the very beginning my husband was torn between discipline as in 'it's only stomach-ache: tell him to get going go to school,' My husband lost his leg and is an amputee and he said, "I've got one leg and I have to do this that and the other".'

Kathleen shares her ambivalence about the cause of her son's unexplained pain and gives a picture of her role of advocating on behalf of Michael inside and outside the family. Illness experiences have been a feature of her married life with her husband's amputation and Michael's older sister diagnosed with leukaemia.

Parental Sacrifices as MUPS takes over family life

If pain in an individual body can be 'all-consuming' and a destructive force in young people's development, interests, and future life trajectories, parents' stories of living with a child with MUPS raised a similar notion of an 'all-consuming' impact on their life, and family relationships generally.

The other side of the story of increased closeness and solidarity between family members when living with MUPS was the cost to parental relationships and siblings in terms of their needs and desires. Several of the mothers spoke of the sacrifices some of which may have been driven by guilt or self blame:

'I took a week off of work for that I was furious (3) used to sleep on this camp bed in the nursery with a sandpit and for no reason only that she did have this pain.' (Carol)

'We live each day for each day now. We don't look for the future because we don't know what's there... I know when Julie first [be]came unwell I felt I had no life myself because my life was caring for her.' (Sue)

Within the parental accounts one senses weariness, fatigue, and a little anguish at having to devote so much time and energy to their teenager's condition. The parental sense of duty to their child can be strained at times because, as in the experience of the two families above, the condition 'has taken over' and what is being sacrificed is the parent's own sense of self, present activities, and future hopes; impacting upon all family members. For Carol and Susan the pragmatics of living with a condition meant total sacrifice and they may have difficulty relinquishing responsibility for caretaking and embracing a more flexible parenting style, which allows the experience of life to take its course outside the demands of the condition.

4.1.2 Doctors' Focus Groups

Table Three: The Main Themes

Doctors have either no, or very limited training in MUPS

Paediatric doctors explain they had no formal training in MUPS, but believe that specialist knowledge of the condition is held within CAMHS. Conversely a senior trainee doctor in CAMHS reported that opportunities to access knowledge and experience of MUPS is very limited within child and adolescent psychiatry.

MUPS – The Doctor's Dilemma: exploring aspects of clinical certainty and ambivalence

Doctors are trained to make people better, so are faced with a dilemma of whether to continue investigations despite the absence of medical evidence when faced with young people with intense pain/symptoms and distress?' For busy community and hospital paediatricians time constraints and lack of progress investigating symptoms can result in frustration.

A trend towards increased specialisms in paediatric hospitals – who takes responsibility for MUPS?

The increase in specialist paediatric services can absorb resources from generic services. Specialisms require a diagnosis to access the service in both paediatrics and CAMHS. MDT teams are focussed upon their specialist primary tasks, all of which is disadvantageous to young people with MUPS.

What would make a difference for MUPS sufferers and their families?

Community and hospital paediatricians and liaison psychiatrists shared many interesting ideas about how improvements could be made in the care of MUPS sufferers and their families. The community paediatricians spoke of the needs of patients and the dilemmas of clinical management (which perhaps reflected a greater focus on assessment of medical conditions in childhood and adolescent health) whereas the paediatric liaison psychiatrists appeared to have a more holistic view of MUPS sufferers and their families and included an approach of

curiosity towards the stories of experience of their patients.

Doctors' Focus Groups

The experience of focus group members of MUPS varied from very experienced, to limited or no experience. The two child and adolescent psychiatrists were considered to be 'experts' in MUPS in their local areas and a consultant in paediatric rheumatology who attended the second group is seen by colleagues to be the local expert in CFS/ME for the region.

In both groups the participants generated a thoughtful and at times creative discussion and leading me to reflect upon the usefulness of focus groups with a wider multi-disciplinary membership in future research.

Doctors have either no, or very limited training in MUPS

All members of the doctors' focus groups from advanced trainee to consultant level with 30 years of experience lamented that they had little or no formal training in MUPS, and that their first engagement with children and families with MUPS was as newly qualified doctors in outpatient clinics or as ward admissions. An experienced community paediatrician shared her views about the dearth of training in the field of MUPS and its impact upon the service offered:

'As a trainee there is very little [training] on MUPS. I don't think I remember particularly in medical school...I'm just thinking back to being a junior doctor and SHO and I can't particularly remember it being talked about at all...'

(Dr. L)

The issue of time in order to develop a more holistic approach to training that would be able to incorporate complex conditions like MUPS has reduced with the narrowing of opportunities for medical trainees to experience psychiatry or psychological approaches. In addition, the associated increase in specialisms

based purely upon individual diagnosis such as paediatric neurology or eating disorders in CAMHS increases the possibility that MUPS sufferers will be increasingly isolated from services since they are without a meaningful diagnosis.

‘...as an endocrinologist for example there isn’t a great deal of time for stopping on the way to do a little paediatric mental health....a career path is determined very much for you now, rather than perhaps in a days of being a registrar/senior registrar which was my training you know, its longer and you have a chance to take a bit of time out to do something a little different.’
(Dr. L)

Dr. L felt she benefitted from having had a child psychiatry placement during the ‘old system’ of training, which broadened her horizons in terms of the relationship between physical medicine, mental and family health. She laments the passing of the longer and more diverse form of training and the dangers of increased specialisms, which will have a negative impact in terms of informed learning and understanding of MUPS for the diagnosing doctor and treatment specialist.

An experienced consultant paediatric gastroenterologist recalled that he had worked with a psychiatrist as an SHO, which had a long-lasting impression upon his practice. He suggests that ‘modelling’ in training remains significant. His use of an older psychiatric term of ‘hysteria’ to describe the symptoms has informed his practice. However, I also sensed that he has not been able to engage with CPD in relation to MUPS, which was a disappointment as paediatric gastroenterology has a significant clinical population with unexplained stomach pain.

‘I did four months in child psychiatry in a Children’s Hospital and during that time I came across a number of what we called in old fashioned terms ‘hysterical’ conversion symptoms and I think that his way of dealing with those probably informed me quite a lot with those type of cases.’ (Dr. C)

Dr. L and Dr. C's enthusiasm for psychiatry placements in the past was not endorsed by Dr. S, (the SPR in Child Psychiatry), and his supervising consultant Dr. M, in relation to contemporary training in MUPS. Dr. S's experience has been that he had very minimal theory/practice training despite having to engage with young people and families with MUPS throughout his rotation. For Dr. S there was no substitute for working with families and the network around the child and family in a clinical setting.

'I think that is another thing but I would say that in child psychiatry training is insufficient, whether a child psychiatrist would deal with kids like this is questionable unless you are in medical community setting it is quite difficult, do you feel that you had a sufficient training?' (Dr. M)

'I do not think we get training in the assessment of these sorts of problems or even to explain a situation when a diagnosis cannot be given: it is about the experience of being with them...I feel the families are putting you under quite a lot of pressure, or the system is, and I think it seems to create quite a lot of angst in various bodies that are involved... apart from paediatric liaison, the pathway is much clearer for the sort of psychiatric conditions like schizophrenia than MUPS.' (Dr. S)

It is not surprising that there is no common theoretical understanding or approach to MUPS across Paediatrics and CAMHS services, given the dearth of training in both fields. What I found of particular interest in even the most experienced paediatrician's accounts was the notion that the 'expertise' of MUPS lies within the mental health/psychological field. This perhaps subconscious disassociation of mind and body is symbolic of the dominance and success of the reductionist medical discourses in Western societies, which are an implicit obstacle for professional collaboration over MUPS.

MUPS – The Doctor’s Dilemma: exploring aspects of clinical certainty and ambivalence

Doctors continue to have a level of prestige in society. As Frank (2005, p.78) has observed, ‘Many ill people when they are patients, harbour an intuition that their physicians know aspects of their suffering as no one else can. Among all the words that shape an ill person the physician’s words have particular significance.’

The role supported by a wealth of biomedical science invests the doctor with authority and a confidence to act with some clinical certainty. However, faced with the complexity of conditions like MUPS can reveal ambivalence, anxiety and ambiguity in a doctors practice.

The paediatricians in both groups highlighted many challenges and dilemmas for their professional colleagues in managing young people and their families with MUPS and the professional network that is often involved in acute cases.

A community paediatrician opened the first group discussion by identifying the differences between a diagnosable illness such as cancer, and MUPS, and continued with his analysis of a number of issues for paediatricians to consider:

‘From my point of view there is a challenge of working with the families combined with the challenge of working with the institution the young person is part of, be they health, education or social services, and trying to decide how to work effectively with each of these bodies... Institutions sometimes understand the child as a malingerer...or young person thinking that they have the needs of an infant, but they are fully wrapped up in a body of a child or teenager and it is how you deal with all these different emotional health issues that is difficult.’ (Dr. D)

Several of the doctors demonstrated an awareness that families with MUPS presented in ways that contradicted the core principles of the medical role and training. Unlike diagnosed diseases, which had clear treatment regimes and

cultural expectations, MUPS was considered more complex to deal with because it involves dealing with a broad spectrum of sometimes contradictory perceptions from the child, parents, and the professionals.

For hard-pressed clinicians time constraints and lack of progress investigating symptoms can result in frustration. Other cultural forces may also combine with personal professional beliefs that doctors may hold about managing young people with MUPS, as Dr. L suggests:

'I think as paediatricians we are very used to making people better and I think often when dealing with these kind of things you are not absolutely clear in your own mind exactly what you are dealing with, and not absolutely clear what treatments are required –you know, who best to help. I think there is definitely frustration there, it is not straightforward: it takes time; ...there is a lot of liaison to be done; when you are busy you need to attend to those things but it can be quite difficult ...enthusiasm for these kind of problems wanes a bit; it can be hard when from the family's point of view things are no better.'

The Paediatric Gastroenterologist revealed a cautious approach in assessing young people and their families in his department. He highlighted a significant challenge for paediatricians when dealing with MUPS patients: how far to go with investigations when the young person and family continue to request a search for a cure when medical/clinical evidence suggests that an organic cause is unlikely to be discovered? He shares a clinical experience when he diagnosed unexplained symptoms in a young patient who later was discovered to have a tumour.

Stories of missed diagnosis may predispose doctors to continue with investigations, and can contribute to the clinical ambivalence and anxiety. These feelings can increase when practising in a culture of litigation and disciplinary action from British Medical Association or complaints from patients for clinical misjudgement or poor practice. It also reflects society's idealisation and infallibility of the doctor's role, and this paediatrician has given some

thought to this notion when he comments 'medicine doesn't have all the answers'.

'I can think [of] cases where I thought it has been unexplained and then it has become clear it hasn't been...basically a child's parents wanted a diagnosis of reflux, I advised them that this was not the case, and so they went elsewhere and the advice was confirmed that it wasn't...then they saw a doctor who decided that just in case he would do a brain scan and it showed that this boy had a very rare brain stem... I think this issue highlighted that you will find things that you cannot explain your challenge is to try, well to control the anxiety within the context, and not actually send everyone off for every investigation under the sun, which has no connection with the problem. My general view is that investigation increases anxiety rather than decreases it, but it is a burden.' (Dr C)

There were a number of comments which referred to a spectrum of interest by both community and hospital paediatricians in relation to the kind of service young people and their families receive once they have accessed paediatrics. A Consultant Paediatrician seen as an expert in CFS/ME gives a perspective of the personal as well as professional approaches to MUPS in the hospital.

'These are group of patients who some people loathe working with and other people are neutral about it. Some people enjoy it and that doesn't always parallel the competency; some people are actually quite competent in managing these groups but don't enjoy doing it. ...I think what tends to happen if they see somebody who doesn't enjoy managing them they tend to discharge them quickly and then they end up with somebody else, and if they don't enjoying managing they will discharge them again and in this way people go through various specialities.' (Dr. H)

I reflected upon the issues of time, very large caseloads, and years of training and practice in assessing pathology are possibly constraints for paediatricians and most likely GPs in identifying non-physiological triggers for MUPS. I wondered about the utility of introducing concepts from Narrative-based

Medicine (Greenhalgh et al. 1998; Launer, 2002) in respect of engagement and history-taking of the family. This may lead to a more resource-focussed engagement with families by paediatricians and an awareness of the impact of emotional and psychosocial influences to add to their physiological appraisal.

A trend towards increased specialisms in paediatric hospitals – who takes responsibility for MUPS?

The hospital paediatricians made a number of comments alluding to the ways in which specialisms within the hospital act against the early assessment of MUPS and create obstacles in working together to assess and manage young people conjointly.

Dr. H explained how specialisms can act against holistic care:

'I think in our organisation symptoms are compartmentalised, people think in linear ways: you know, gastroenterology; neurology; rheumatology; and are not thinking holistically or cross-laterally in the other dimension either in relation to age or needs if you can get yourself into a category you might then access a certain professional – without having a diagnostic category you don't see certain people.'

Dr. H highlights how, with an increasing emphasis on specialisms and reducing resources, young people with MUPS without a medical diagnosis are severely disadvantaged in a children's hospital setting. Some paediatricians might need to 'label' young people in order for them to gain access to the services that they require.

'I think medicine is so specialised now and I find it often quite surprising how many different investigations have been done at the same time and how everybody just focuses on just their own speciality: so you will have an eye doctor; an ear doctor; a chest doctor to flag these patients out and to consider MUPS as a differential diagnosis from the beginning, rather than

diagnosis by exclusion. If you keep that in mind your thinking becomes much more open-minded.' (Dr. M)

Dr. M, a child psychiatrist, comments on the increasing number of specialisms in child and young people's medicine. She remarks upon the number of investigations young people may have undergone – many at the same time – and how each specialism is focused upon within the parameters of its own primary task, with little or no reference to the medical history or the pattern of previous or simultaneous investigations. Accordingly, there is no-one to keep the 'whole' child in mind.

It is interesting that there is a common agreement between Dr. H and Dr. M about the increasing delivery of specialist services in both paediatrics and CAMHS. Specialist services based upon individual diagnosis and symptoms naturally exclude MUPS sufferers, who as well as not having a diagnosis may also experience multiple symptoms.

Both these experienced clinicians are taking positions critiquing the clinical trend towards specialisms within their respective institutions. They are both cognisant of the lack of systemic and holistic thinking in planning services for young people. However, neither clinician identifies a need for closer collaboration between their respective professions.

There may be an underlying narrative template that increases competition for 'expertise' with a condition such as MUPS between child paediatrics and psychiatry. This implicit rivalry could counterbalance the logic of collaboration and act against the interest of more positive clinical outcomes for young people and their families.

What would make a difference for MUPS sufferers and their families?

The focus group members generated many ideas about improving the approach to health and social care for young people and families with MUPS. Despite the

growing research interest in MUPS there was no direct reference to an evidence-base and the ideas were generated from clinical practice. Some of the following comments included useful ideas for those who might be planning services in future decades:

'I think new services across the board are required to address the needs of these young people. There is a lot of disability that accumulates in young people in addition to the MUPS. I think it's quite challenging. And obviously the whole system around the young person, working very closely with the paediatric teams, social services and education.' (Dr. M)

'You have to create the services around them from different services, because while each child has similar groups of problems they have different needs and that's the main sort of thing that is the most difficult to create.' (Dr. L)

'We ought to actually talk about what pathways should be for young people with MUPS...my view is there are age boundaries: there is that sort of 10 to 12 plus – you can work more with a young person and empower them; whilst MUPS with kids under 10 is a very different ball-game. We could start a foundation of getting something better under an adolescent umbrella which, if we got it better for them, then I suspect this would lead to something better for primary school-age children?' (Dr. H)

It was very useful to have two Consultant Child and Adolescent Psychiatrists in the focus groups, as they introduced a broader perspective to the discussion. They both had lengthy experience in working with MUPS sufferers and their families. They are frequently asked to engage with patients towards the end of a long process of medical investigations for young people and families. If the paediatricians were concerned with managing MUPS, the two psychiatrists were focussed upon the complications in the experience of MUPS sufferers and their families. It was also striking that they introduced theoretical ideas from other disciplines outside of medicine and this appeared to give them a broader area for manoeuvre within their practice.

Dr. S introduces some ideas around what kind of theory influences her practice:

'I suppose for me what I am doing is going in with a really open mind as to what might be an issue and what might not be, and trying to understand it. I was thinking theoretically, it is quite often thinking developmental theories that is most helpful – systemic theories and family life cycles – and what becomes really helpful is defence mechanisms which are terribly old-fashioned in terms of psycho-analytical ideas...I think MUPS are there for a reason and we should not dismiss them or try to knock them out of the way because they are probably serving some function to the young person and family.'

Dr. M explained her view of the importance of pacing when engaging MUPS young people and their families:

'It's almost like you have to pace the psycho/social interventions: the way you pace the medical for physical problems, because if you intervene too quickly you lose the family really. If you intervene too slow it's not right either; so it is sort of like you have to continuously review what you are doing session-to-session.'

Dr. M's account, although in a separate group to Dr. S, mirrored her comments about the need for an open mind by the clinician when engaging with MUPS families. In this sense, an 'open mind' may be understood as being aware of the multiple stories from young people, families and the professional network but not to settle upon a truth too soon, if at all. Without the direct naming of concepts Dr. M also suggests an openness to other paradigms such as systemic, social constructionist and collaborative therapy when working with MUPS, which requires flexibility of positions in the therapeutic approach and a willingness to suspend the more traditional doctor role/beliefs from within a medical framework.

'What surprises me is how chronic most of these cases are and how disabled the children are really. Although there is no clear medical condition the level of social, education or family disabilities and other aspects of the child's functioning are just incredibly affected, [and] because they are usually a quiet group their issues don't get addressed at school – we see kids here who have been out of school for two years and nobody has ever addressed that.' (Dr. M)

The comment that young people usually are a 'quiet group' should be considered alongside the parental accounts which concur with the view in terms of the loss of confidence and diffidence of their children in the public/social domain, but also refer to their children's voices and expression of emotion (often of distress) as being louder in the domestic, private and more intimate relationships of home. Dr. M's descriptions of the chronicity of the condition in some cases suggests that she is aware of the emotional levels of distress in the private domain and the potential for marginalisation and invisibility of this group by public institutions.

'I think it really depends a lot on their previous journey, and how the referral was made that supports the family's engagement with psychiatry. From the young person's and family's perspective it can mean that it is a psychiatric condition and they will say: "What is it that causes the problem? If it is not medical then there is something not yet been discovered"... To hold on during a session to the position that it is neither psychological or just medical: it is both; and pursuing the line it's either/or is not helpful... From a personal perspective in terms of working with the families it is about learning to be with them and learning to almost change the role as a doctor – because as a doctor you are expected to make people better, to give them advice, to do investigations, look for medicines and so forth – but really it is about much more collaborative work.' (Dr. M)

In this extract Dr. M gives us a window into her work with young people and families with MUPS and ways to manage dialogically the patient's demand for a linear medical explanation, while joining with the family in a therapeutic context.

She advocates a both/and collaborative approach and sees the either/or approach as unhelpful referring to her work with families when physical follow-up has ceased after referral. Dr. M is aiming to challenge an illness-dominated narrative and encourage professionals and families to consider other non-medical therapeutic possibilities, but she also advises that young people and parents should have the opportunity to explain their experiences of MUPS and relationships with medical care. Perhaps more needs to be understood about the dialogue arising from the different positions.

Deleuze's distinction between 'every-day concepts' which can reduce difference and 'philosophical concepts' which can expand difference and enable new possibilities, may be a fruitful way forward 'so everything that is not the problem story becomes a site for new meanings that can be ascribed more useful and more agentive' (Carey et al., 2009). As both psychiatrists point out, pacing and introduction of 'difference' into their therapeutic dialogue with MUPS sufferers and their families is crucial in facilitating change.

4.1.3 Healthcare Professionals' Focus Groups

In their respective support roles healthcare professionals are more likely to experience the every-day dilemmas, emotions and stories of young people and their families than the medical doctors. It is increased closeness with young people both in educational, play and daily care issues which makes their accounts very relevant to the research aims.

Table 4: Main themes

Bearing witness to young people's and parents' experiences of MUPS

Nurse specialists, teachers, physiotherapists, youth workers and play therapists are often ideally placed to bear witness to see or hear the experiences/stories of young people and families with MUPS. Many will respond with sympathy and care, yet personal/professional resources and pre-understandings can constrain the response, and thus reduce the potential for healing interpersonal moments.

A hierarchy of diagnosis in the clinical culture of the children's hospital

Young people with MUPS and their families can be given lower priority than patients and their families who do have a diagnosis. MUPS is held in low status in comparison to high status disease/illness. The perception that MUPS sufferers lack motivation towards treatment or reject positive reinforcement about perceived improvement can be a challenge for nurses, physiotherapists and other hospital support staff trained in restitutive model medical care.

Caught between mind and body

The culture in a children's hospital is largely focussed towards the treatment of disease and restoration of physical health. The healthcare professionals who come into contact with MUPS are sometimes caught between conforming to the physically-orientated care, and involving themselves with a holistic approach to engaging with MUPS sufferers which involves much time and emotional effort.

The meaning of distress

Healthcare professionals refer to their ideas as to the meanings of distress in young people with MUPS. There are moments when the healthcare professionals seek to understand and connect with MUPS sufferers' distress in ways which involve careful listening and non-judgmental empathy.

Bearing witness to stories of young people's and parents' experiences of MUPS

In the following extracts we can appreciate that nurses and professionals allied to medicine are frequently approached by patients and family members with dilemmas or intimate details of the experiences, feelings and troubles with regard to the young person's symptoms or treatment. The professionals often have to explain and process the feedback from doctor's consultations or ward rounds. Healthcare professionals can take their pre-understandings into conversations with patients, which may be a reason for one nurse specialist,

Linda, reporting that young people feel they are not listened to. Feedback from patients is sometimes heard by healthcare professionals as information leads to advice about change in the individual's or family's beliefs or behaviour. The timing of this advice may not always reflect an understanding of the young person or family's distress.

'It's all about the language that the doctor gives at the first consultation isn't it? I know I have missed out in the past and it leaves you on the back-foot and then you are faced with a telephone call and distressed patients in the clinic the next day.' (Linda, Nurse Specialist)

'They talk to us about people not hearing them; they talk to us about various things in their symptoms. If someone starts to focus on a frozen joint or whatever, you know on something, they seem to start saying "Well it's not just my arm". If they are challenged on the point they will back away from it and bring something else to the table.' (James, Teacher)

'Its back to that listening thing; "But you are still not listening" again "Its not just my arm, it's my leg, it's my leg, it's my head: you are still not listening".
(Linda)

'I think you can be caught in the conflict that you are hearing this from the parent but you can never be confident that you are hearing this from the voice of the young person... You feel the parent taking control of everything and the child doesn't get their say.' (Rebecca, Nurse Specialist)

Generally the tone and content of the accounts of healthcare professionals' experiences of young people and their families was presented as first-order information delivered in a second or third-person story. The dilemma about who to believe between parents, young person or doctor revealed the constraints of a modernist genre of single truth and objective realities, rather than hearing parental accounts as authentic to the parental perceptions and the experience of their child's predicament.

Healthcare professionals may hear parental accounts of their child's experience as a 'truth' which they may assume are distant from the child's 'real' experience of MUPS. A dialogical and narrative theoretical framework could assist healthcare professionals to consider other possible meanings or intentions in parental and young people's accounts and to contemplate the idea that stories can contain contradictory perspectives about the same event or experience, but there is a 'truth in the telling'.

A hierarchy of diagnosis in the clinical culture of the children's hospital

The group reflected on how MUPS patients were seen as far less deserving within the hospital population. The discussion on this subject revealed a mixture of strong feelings and beliefs about which patient group was most deserving of care and treatment – suggesting, as Cheryl Mattingly (2008) has described, the existence of a hierarchy of diagnosis with certain conditions attracting a higher status of care, such as cancer in comparison to MUPS, or self harm.

The external picture one gets of a children's ward, is of a benign clinical environment with busy, self-contained doctors and nurses going about their daily business of making patients better. The backstage stories and minutiae of interpersonal relationships and responses to unpredictable events on the wards reveal at times a ferment of anxiety, and at times conflict, between different MDT professionals representing different specialisms.

The focus group discussion gave a glimpse of these backstage dramas. James, the teacher, offers a perspective into these processes including his own strong emotions about diagnostic inequalities, and what he sees as prejudices against MUPS young people and their families:

'I was told that so-and-so (who happened to be an oncology patient), is having a birthday party this afternoon. The oncology nurse said, "You can't bring Lucy because she is miserable". Well Lucy was here with depression.'

Well I was utterly incensed and tackled the person afterwards. I said, "If I said to you I am doing this this afternoon, but I am not inviting your patient because they have got no hair it is as logical as what you have said to me... She genuinely hated my kids because her kids were so ill and that is where the focus should be, and my kids were just wasting everybody's bloody time and being naughty. I couldn't get across to her that my kids had an illness.'
(James)

Rebecca (Nurse Specialist) stated:

'It is different with other illnesses; nurses particularly like to do things, they like to put a bandage on, take a temperature: they like to do something to make it better. So when they are presented with a young person who has no clear diagnosis and shows a lot of emotional distress they get frustrated.'

The possessive nouns that James uses in this extract give an indication of how professionals attached to different specialisms can identify strongly with their respective groups of children and young people. It is interesting how Rebecca responds to James' anguish by identifying nurses' priorities as 'doing tasks' to, and for, the patient's physical care in line with the senior doctors' treatment protocols. Rebecca responds to James' strong feeling with an explanation spoken in a moderate and rational tone about the role and priorities of her nurse colleagues.

Considering the oncology nurse's perspective in James's story, I wondered if she is working with a group of young people some of whom will die, or who undergo unpleasant treatments, painful and exhaustive treatments. She may be contrasting this experience with young people with MUPS, who appear to have lost interest in life without a diagnosis. Similar moral judgements by healthcare professionals are sometimes made by juxtaposing the very sick child with a young person who has self-harmed, in the paediatric hospital ward context.

One of the sources of the different positions which were identified in James's story can be located in the notion of the hierarchy of diagnosis reinforced by biomedical hierarchy in professional roles. For example, medical surgical patients are afforded the highest status, whereas patients with a contested illness who require rehabilitative non-medical approaches have less status and are thus given less priority in the hospital culture.

Caught between mind and body – ambivalence in healthcare professionals working with MUPS

The following extracts form part of the group discussion, which focussed upon where professionals direct their thoughts and energies with young people with MUPS. I sensed that the group were caught between responding to the institutional needs (bed-blocking) and the priority afforded to physical health care and responding compassionately to MUPS sufferers' physical and emotional distress.

Researcher: *'James was speaking about the way that some clinicians explain the condition by suggesting "If is not physical it must be psychological" what are your thoughts on this?'*

Linda (Senior Nurse): *'I think from experience it needs to be integrated because they come to us with a physical problem in their minds, they have been referred around before getting to us; seeing lots of different people. You have got to keep them and help them.'*

James (Teacher): *'If they have adopted a poor stature, or a poor positioning of a limb for years, then they can have ligaments stretched or shortened, and they genuinely have the physical symptoms at the end [even] if it didn't start physical.'*

Linda: *'Or there is the vomiting when they are underweight then they need feeding: there are always lots of physical things that can happen.'*

Andrea (Senior Nurse): *'I don't feel in this job that the consultants would say that it is the end of our bit...we might be holding them back, we just don't know do we by keeping them physical? Just a thought.'*

Linda: *'Which goes back to your bit where you said you have to push them to another phase.'*

Rebecca: *'Sometimes you have to think about the physical issue there as a prop to help them get better don't you? That is their tool.'*

In a literal sense the group consensus appears to be that to divorce the mind/body approach from young people's care would not be therapeutic, but then a case is made for giving priority to the treatment of the body, which is what the patients want (perhaps a more comfortable territory for some nurses, OT's and physiotherapists). The rationale presented for this is that working with the physical symptoms has better results as it is closest to the patient's mind-set.

However, focussing the treatment upon the body raises the question of how long to proceed with this approach or whether to push them 'into another phase'. I understood 'another phase' to mean to reverse the young person's view that change or improvement will come from engagement with rehabilitation rather than remaining wedded to the idea of a medical cure.

I think it would have been a welcome addition if the physiotherapist had been available, as their views on rehabilitation would be of interest within such a discussion.

The meaning of distress

Although I was surprised by the amount of managerial evaluative stories of MUPS sufferers by healthcare staff, there were moments of personal and human understanding and compassion, which were triggered by the moderator's question:

Moderator: I suppose I was thinking 'what distress' when you said sometimes that people want to move on but then sometimes people don't want to-what do you think that distress is about? [Long pause]

'I suppose one of things it could be is that the child is not living up to what their expectations due to abdominal pain or whether it is not being able to walk... the child feels different from other children, but sometimes there are emotional things going on within the family or school... there might be distress from a child about something that is happening in the family that causes an illness, a pain or whatever.' (Linda)

'You have to say, "I believe you; I feel that that is the phase you are in..." I was saying earlier about joining them on their ground, you know: "I am genuinely listening to you, I genuinely understand what you are saying" and gain their confidence... "I know you are really tired today, but I think we can go to the classroom and yes we will take it easy, and yes, we will acknowledge your tiredness.' (James)

Linda and James showed empathy and spoke in a softer tone in response to the moderator's question. James gives a picture of his emotional posture in the classroom identifying the young person's fatigue without challenge. In these moments, I would suggest James is engaged in 'witness practice' Shotter (2012), an important posture in working with some young people with chronic illness and MUPS.

4.2 Summary

The thematic analysis has produced interesting themes from young people, parents, and healthcare professionals. It is useful to compare and contrast the themes that emerged from the young people, parents and healthcare professionals' focus groups. The-parental and young people's stories focussed upon non-diagnosis of symptoms by doctors, and judgemental 'finalising' comments in the initial medical interviews, which left some young people and their parents with strong feelings of epistemic injustice. For most young people the effect of not receiving the legitimacy of a diagnosis left them with on-going pain/ symptoms which they struggled to explain to themselves, and with their credibility and integrity damaged. Parental reactions involved attempts to repair this injustice by taking up an advocacy role with medical and educational institutions.

The doctors in this study were secondary and tertiary paediatricians and liaison psychiatrists and were not the diagnosing doctors. Paediatricians highlighted the lack of medical training and sufficient training in MUPS, combined with lack of time to devote to a clinical population that they thought could be very time-consuming. Systemic problems were identified with the identification of the increase in specialisms in child health and child psychiatry. These developments in both organisations were considered to further marginalise MUPS sufferers.

The thematic analysis of the stories of young people, parents and healthcare practitioners who live and work with MUPS brought to mind Goffman's (1959) 'Dramaturgical Framework'. Goffman suggested that everyday human interactions are compatible with theatrical roles and performances. In terms of social interaction there is an on-stage arena where actors perform in front of an audience. Meanwhile conversely, back-stage the person can be herself and relinquish the roles they may play when the audience is present. The off stage is where the actors use an 'aside' or a glimpse of the back-stage self while the audience is still present.

The focus groups were successful in bringing forth themes from the 'back-stage' of young people, parents and healthcare professionals that belie their public image of the alexithymic family and the infallible clinician. Young people and parents disclosed the distress about their isolation impacting upon their wellbeing, parents disclosed guilt, self-blame and doubt about their child and parental roles, and the healthcare clinicians revealed frustration anxiety and ambivalence about their work with MUPS sufferers.

Hanninen, 2000, suggests that there is a quality to drama in narratives that introduces plots into the flow of experience, narratives represent events and experiences as interconnected, and in this way causes and meanings can be attributed to experience.

It is my hope the DNA will be able to unpack more about the implicit and explicit stories that MUPS sufferers and their parents construct in the face of external difficulties. In addition, it raises important questions such as do MUPS sufferers, parents, doctors and healthcare professionals hold their own in competing versions of the plot? And what can be discovered about 'what is at stake' within their stories?

5. CHAPTER FIVE

5.1 Dialogical Narrative Analysis

Unlike a good deal of social science research an aim of DNA is to expand the understanding of the story rather than to 'master' it, and as such it clearly situated in the hermeneutic approach to analysis. The way I approached the DNA of the characters in the wider narrative of MUPS was to keep in mind how the stories of focus group participants shaped their experiences as much as how their experiences shaped their stories. Bad, negative or meaningless stories often emerge because there is an inherently non-relational aspect to them; these kinds of stories discourage the characters 'from moving to another story that presents the same content from a different perspective' (Frank, 2010).

Matthew – A Story of Struggle for Narrative Reconstruction of Self

Matthew (19) is a thoughtful and articulate member who attended both of the young people's focus groups. He was 14 when he first experienced symptoms, which were initially undiagnosed for six months. Matthew lives with his mother, Dorothy, a part-time maths teacher and his father, Andrew, who was a senior lecturer prior to retiring early due to ill-health. Other family members are Peter, who is at university and Matthew's paternal grandmother aged 91.

Mike Bury's (1982) argument that chronic illness constitutes a 'biographical disruption' to a person's life and Gareth Williams's (1984) interest in 'narrative reconstruction' following chronic or acute illness, are both very significant concepts when applied to the experience of young people and their families who live with MUPS. For the young people in the focus groups the 'biographical disruption' would endure for a number of years; as was the case for Matthew whose road towards reconstructing a positive sense of self has been long and seemingly unending.

'...hmm, yes. It certainly made a sharp difference to me since I was an ice skater. Before I got ill I was active: like walking up hills and mountains and those sort of things, so it made a sharp difference...it knocked me back down quite a lot. ...I was skating going towards my bronze certificate at that stage then getting worse and worse...slowly cutting it down until I wasn't going really. So in a way it was a sharp decline and in another way fairly gradual.' (Matthew)

Matthew's pre-illness memory was of a young boy with a lot of physical energy and talent. Whilst these pastimes were not team sports they gave him a sense of pride and achievement. His vague memory about whether the loss of capacity led to a sudden or gradual withdrawal from physical activity, left me wondering if Matthew may have strived to maintain his physically active life before realising that his symptoms overwhelmed him.

Healthy life stories are based on temporal sequence: illness can dissolve this ordered structure of time. Matthew's story quickly moved on to describe the impact of the loss of physical capacities due to the illness, and how it may be easier to adjust to illness if you have had pastimes which involved less physicality; for example chess. Most of the young people's accounts shared similar brevity to Matthew's in terms of their descriptions of life before the illness, as if the recall of a time when they had full energies was painful to recall.

'Yes, it must be a year or two – and a half – something like that before the first collapse when I was 14... It was first to put down to psychological then to my damaged stomach from my four-month infection... It first came on with chest pains before that, then collapsing, then not being able to walk, weakness, fatigue, headaches, migraines all that sort of thing – concentration, memory loss – and it got worse and worse until I got the diagnosis – the time-scale has gone, hence the bad memory.' (Matthew)

Matthew's 'memory loss' about the timing of when he stopped physical activities and the initial experience of symptoms may also reflect the temporal discontinuity when one has to adjust from a healthy identity to a life dominated

by illness. Matthew uses the word 'collapse' to denote the sudden onset of symptoms suggesting a mind/body experience; pain, fatigue and loss of mobility combined with the loss of concentration and memory. The perception of the loss of both physical and cognitive capacities were equally distressing for Matthew. For some young people the trigger for the 'collapse' can be innocuous, gradual or without mental or physical trauma.

There are a number of metaphors that have been generated within illness narratives of sick people in an attempt to re-establish meaning to their experience. Hawkins (1993, p.6) has highlighted four: 'battle, the journey, the re-birth and healthy mindedness'.

MUPS sufferers and their families can feel anguish when they can see or hear healthy professionals speaking about positive illness trajectories. In Matthew's situation and for other MUPS sufferers the 'collapse' or 'fall' from health into illness is significant. The metaphor of a 'collapse or fall' may be frequently used in common language 'I fell ill'. For many of us who 'fall' sick we are reassured by the cultural restitutive narrative which predicts a return to health once we have received medical advice and treatment. For Matthew and some of the other MUPS sufferers in the group 'the collapse' takes on added significance because they cannot draw comfort from this physical illness trajectory and there is an absence of other cultural stories to assist them through their distress and feelings about the indefinite nature of the condition.

'I think when you first stumble into it that [it] was incredible, acute pain; just crippling on the floor sort of thing but (1) after that burned out (4)...the pain didn't bother me that much. I have had something for a long as I can remember so it was the movement; loss of being able to do things (3). I remember sort of just um, nothing there really; not really emotions one way or another, just this kind of flat numbness, sitting still and not doing anything: can't get up; can't do much; don't do much; sort of existing really – not much else for as long as I can remember... Well the only healthy thing I was doing was processing my problems. (Matthew)

Following the collapse, Matthew describes the subsequent phase that we might describe as existential or the phase of 'brute experience' (Mattingly, 1998), which is anti-narrative. Matthew's description of his experience as 'flat numbness', would indicate that he has not yet been able to reconstruct and understand illness that makes sense to him as a sequential next part of his life story. The above extract is typical of Matthew's style of narration when relating his experience. Matthew's articulate yet 'cerebral' style of describing his experiences left me with the impression that he had slightly distanced himself from the experience he was describing. The stories highlight Matthew's loss of direction in life or telos, whereby any re-construction of a narrative thread becomes difficult for him to join with other piecemeal threads.

Although there is some sequencing within his account, each activity appears disconnected from his sense of identity. Despite going through some daily motions such as eating and typing at the computer, he describes feeling overwhelmed; using language which suggests he is dislocated or in a vacuum; 'nothing' 'numbness' as a result of initially acute 'crippling' pain and then 'burnout'. One gets a sense of more than isolation in the experience perhaps a dislocation with his surroundings, an 'anomie' as described by Emile Durkheim, in his studies on depression, whereby the formal structures and routines within the family and community are threatened to such an extent that it brings forth an existential crisis in Matthew's inner conversations. Matthew sees these inner conversations as the only healthy part of himself.

When asked by the researcher, 'Did you meet anybody who disbelieved?' Matthew responded:

'I had doctors looking in my eyes saying "there is nothing wrong with you". A couple of friends didn't believe it at all; even now there are few people I know that don't really understand...Before I was diagnosed I was wondering whether I have something that is unexplained. Once you know what it is, it doesn't matter so much what other people think, and if they don't believe it: that is their problem I'm afraid...With a diagnosis it was definitely easier: it

gives you a sort of direction to fight it; you have some idea of what is going to happen, what's coming at you. And if you don't know what it is then you start to think that it can get a lot worse: without certainty it is very hard to plan or move on from that, since you are not on stable ground to start with.' (Matthew)

Over the course of the two focus groups I came to see Matthew as someone with integrity and capable of thoughtfulness. The doctors who dismissed Matthew's distress from a position of authority can shape perception and action in a 'kind of reverse mimesis' (Radley, 2012, p.382). The modulation and posture of the doctor's feedback could have been damaging to his sense of self; leaving Matthew without credibility and legitimisation. Thus when a diagnosis is made by a 'listening and interested doctor', it becomes a counterpoint to the disbelief of symptoms by significant others.

A diagnosis is also a cultural metaphor that protects the possessor from 'what other people think' and for Matthew, who had been troubled by personal self-doubt it restored some direction and self-belief. Indeed, Matthew says the diagnosis made little difference in terms of biological treatments, but what appears to have changed were people's attitudes towards him.

'Things changed suddenly in my family, but more through necessity and not any particular perspective changing. My family helped me out a bit more, ...and [helped me to] be a bit more careful about things... I never really talk to people about things; it's just how I deal with things; I withdraw and try to deal with it myself...there are points where not thinking about it is best, and if everyone knew then there is always: 'How you doing?'; 'How's it doing?'; 'How you dealing with it?' sort of questions which just brings it all back to mind... I think it's easier to have some little circle where it doesn't exist, where you just go, and its not there anymore.' (Matthew)

Here Matthew highlights his autonomy which is verging on solipsism; a common theme for group members. The values underpinning this kind of autonomy are 'dealing with things myself' or if this is unsuccessful, 'pretend the problem

doesn't exist': there are times when 'not thinking' is preferable to thinking, but less threatening than 'going public'. Questions about his wellbeing are perceived as 'reminders' of distressing experiences of symptoms, rather than friendly concern, so it is better to create 'a little circle' where the problem doesn't exist.

During the focus group Matthew disclosed that his parents had withdrawn him from primary school to be home educated, because of threats to his brother. He also informed us that his father retired early with MS.

According to Matthew his family changed through 'necessity', suggesting that the family adjusted in pragmatic ways rather than changing or expanding their existing world-views. With the onset of symptoms Matthew believed that other family members became more 'careful' around him. Matthew's description of his friends' responses to his circumstances belies his reticence in sharing his feelings about the condition, as he says they encourage him not to let the symptoms completely isolate him from social activities. However, the reticence he feels about responding to his friends' enquires about his health appears to be connected to his desire to maintain a 'normality' of self to his closest associates.

Matthew and his family appear to value private rational thought, self-reliance and independence, despite life's adversities such as MUPS. Matthew shared his feelings of distress from his inner conversations about the loss of cognitive and physical capacities resulting (at worst) in the loss of meaning and purpose to life. The experience of emotional 'numbness' and vulnerability appears to be in conflict with the personal and family values attached to self reliance at times of adversity. Matthew's preference to manage his dilemmas within "inner conversations" rather than engaging in "external dialogue" may limit his opportunities to access cultural stories that could assist movement beyond the constraints of the "little circle where the problem doesn't exist". *What is at stake for Matthew is the risk of continued reliance on inner voices that may obstruct his access to external dialogue and therefore difference.*

Julie – A Broken Narrative and Meaningful Silences

Frank (2012, p.122) suggests that in

broken narratives, emotions fracture the telling and the listener or reader is left with fragments that do not form a whole...The narratives that concern me are broken; the nature of the experience does not, cannot, and never coalesces into a cohesive whole, as narrative traditions expect wholeness.

Julie (17) is a group member who exemplifies broken and indeed 'thin' stories of a young person's experience of living with MUPS. She lives with her mother Sue, a nurse; Andrew, a businessman who works away from home during the week; and sister Joanne, aged 12. Julie experienced a sudden onset of leg and right arm paralysis. She underwent extensive medical investigations and 'nerve blocks' (a nerve block is an anaesthetic injection in the locality of pain aimed at severing pain signals to the brain); in the hope that physiotherapists would then be able to work more actively on her twisted limb.

Julie struggled to narrate her experience despite her high academic achievements as an A-star student. She appeared to be a considerate listener and bore witness to the other young people's accounts. Yet her own comments were largely perfunctory, with brief comments and silences in response to questions and themes arising from the group discussion. The extracts below are a condensed form of her comments and my sometimes awkward questions to invite her into the group discussion:

Researcher: How about you Julie?

Julie: *Yes I was a dancer. It was quite sudden: I stopped going to school.*

Researcher: So what happened then?

Julie: *It started in my arm and then it sort of spread to my leg and then yes, I had to sort of, was off school until May and then I had to change all*

my A-Levels. But now I am doing three AS levels: chemistry, biology, and photography.

Researcher: Did you do sports Julie? [Julie shakes head] But you were a dancer?

Julie: *Yes, dancing.*

Researcher: I was thinking about asking you what are the biggest three challenges in living with illness that is unexplained, what are the three challenges individually?

Julie: *First challenge was my confidence because it ruined my confidence because I was about 14 when it first started, so obviously I knew what was my life like before. So like I can't dance. Then second one was being able to go places on my own because (.) with my collapsing it could just happen anywhere, any place, and at first I was very nervous (2) gradually I threw myself into it so (5).*

There were a sequence of questions to the group about diagnosis in which Julie responded in short replies suggesting she had been 'worried' when her symptoms had been undiagnosed and 'felt better' once her diagnosis had been given. I remained doubtful about the diagnostic term that Julie had been given, or if the paediatrician had alluded to a physical condition rather than conversion disorder or MUPS. The effect of Julie's short replies made me careful with my questioning and I wanted to remain sensitive to her silence or holding back.

Julie: *I don't want to get to university like saying I have got an illness. Really I don't know: I want to do it off my own bat, any way it is because I do not know. It is quite annoying, really that sort of changes everything really.*

Researcher: Do you think that there are a lot of differences how people talk with you?

Julie: *Yes it's quite annoying, but you show them you're clever; it sort of proves them wrong. I have had to a change set of A-Levels – [I] went off with one set, now have changed to a completely different set. ...My condition feels at a constant level. I don't collapse or anything, you know it's there all the time, and it comes and goes.*

The above extracts reveal Julie's frustration with the external world's reaction to her condition. Like Matthew, she described the onset of the condition as a 'collapse' and felt anger towards the symptoms as they caused a significant biographical disruption to her life; particularly as she had mapped out her academic goals prior to the onset of illness. However, education institutions may perceive her differently because her body is now misshapen and she requires a wheelchair.

Julie is determined to show the authorities that she does not need exemptions and that her inner identity remains strong despite the disability: she has shown that she can be flexible by changing her choice of A-Levels to reach her educational goals, but it remains annoying to her that she had to contemplate changes in the first place. Here Julie shows what appears to be defiance towards her perception of the outside agencies: 'You have to show them you are clever'. She is staking her claim in terms of future career possibilities. For Julie the outside institutions hold the authority/power. She does not want their sympathy or pity (exemptions) and she can overcome the change in rules or standards because of a strong autonomous self. However, although the defiance required may be preserving her autonomous identity, it may also lead to fewer opportunities for inner or outer dialogues to emerge about the impact of the condition on her life.

Julie: *I find it hard. I just prefer to just shove everything to the back of my brain and to get on with everything normally.*

Julie utilises an idiom of speech to describe how she manages emotional distress associated with the physical distortions of her body. Like Matthew, she

works to defend the autonomous self to help her to return to normality. However, her reluctance to join in external dialogue suggests that she will find it difficult to emotionally process the impact of her body paralysis.

When the Researcher asked, 'Do you want to say anything about the responses to the illness by friends or family?' Julie shook her head followed by a lengthy silence.

The silence following the researcher's question was profound, creating a tense moment in the group experience, since the other participants had offered a number of comments about the supportive/less helpful responses of friends and family in their experience of illness. It also came at a point towards the end of the meeting, when young people appeared to be more relaxed with each other and the group processes generally.

In the post session reflection between moderator and researcher we both considered Julie's brief shake of the head and subsequent silence as particularly meaningful and intuitively felt Julie's lack of response suggested 'please don't go there'.

George Drakos (2008) in his study of HIV sufferers approaches silences by examining their narrative context, how silences are linked to external and internal narratives. Drakos acknowledges that some silences are 'not loaded with meaning' (p.100) but a focus of interest is in 'personally intended silences' or silences invoked by external authority.

There are arguments for suggesting that some illness experiences, for which MUPS and HIV/AIDS are good examples, constitute a 'broken narrative' that have not yet been constructed, or where multiple tentative accounts co-exist and compete (Mattingly, 2008, p.171). Julie's silence may have signified that she had previously been oppressed by other dominant or oppressive stories and was holding on to an 'unspeakable dilemma' that systemic psychotherapists Griffith and Griffith (1996) referred to in their work with adult sufferers with MUPS.

In conclusion, I considered it was very brave for Julie to agree to join the group discussion and that despite the view of some clinicians (Dr. Jon Stone, 2012) that it is common for people with conversion disorders not to articulate emotions. I wondered if, given time, and more opportunities for therapeutic dialogue, Julie may have begun to gain sufficient trust to generate a meaningful story about her experiences.

Lillian – Discovering a Quest Narrative Without a Diagnosis

As a tall athletic 14-year old, Lillian was suddenly faced with often elaborate non-epileptic seizures and syncope. She could experience multiple episodes each day, which occurred at home and school. She lives with her mother, Margaret and father, Ray, who separated after a 29-year relationship a year after their daughter's onset of MUPS. Lillian is the youngest of the four children from the relationship. One elder sister remains at home.

Lillian was a very respectful listener and always tried to make thoughtful contributions in both of the young person's focus groups that she attended. Her account of her response to illness was unique in the young people's groups in that she was determined (through actions and thoughts) not to let the symptoms dominate her life; despite feeling extremely frustrated that a clear diagnosis had not been given for the symptoms:

'I used to be quite energetic and because I've got a young brother who I used to babysit for, but because now I get quite tired, I can't even do that now...Well we used to go out with family and also some friends as well and (.) I used to do after school things as well. I don't know if I did too much more: I was more outgoing [coughs]...Um, well at first I went to my G.P. I thought well maybe he's right its just fainting cause just then I was collapsing once a day or something and then it got worse, I came to the hospital um, (.) and I just thought they might find something or not. When they told me they did not know what it was I was kind of upset...I would have liked the doctor's

to listen more to what you are trying to say to them, because at the time I didn't know quite how to explain it to myself and put it down to fainting. And at one stage I thought it was just in my head as well, and um, and I think at one stage I thought they were talking down at us because we wasn't professionals.'

Lillian reports onset of symptoms as having been fairly quick, and initially she thought it was a one-off 'faint.' It is interesting that she describes the subsequent episodes as 'occurring one after the other' but in this part of the group discussion about symptoms, does not offer a name to the symptoms. Unlike Matthew and Julie the focus of the collapse was solely upon the physical in the initial onset.

The story of Lillian's encounters with doctors left her feeling upset because she didn't feel listened to, and felt she wasn't given time to explain what in many respects can be considered as unexplainable. Lillian had a sense that the episodes were more than 'faints'. Like Matthew, her perception was that her credibility was undermined by 'expert' doctors, and without her mother's support she would have not been able to hold her own in the dialogue.

There is a vagueness about Lillian's story of the symptoms which may have reflected in the ambiguity about diagnosis by the G.P. and specialist hospital doctors. This may also be due to an awareness that there is little coherence to her experiences of illness and the failure to have her account of symptoms given any real credibility by the doctors. Additionally, an explanation for Lillian's inability to describe the symptoms may have been due to embarrassment concerning the elaborate non-epileptic episodes, or loss of control during seizures in the presence of the participants of the focus group; her newly-acquainted peer group.

'It made me feel more comfortable with it and I knew I could speak to my mum about how I felt...she was always there to talk to me if I was a bit upset, and like wondered why they didn't find anything or what it was, so I think that helped quite a lot.' (Lillian)

Lillian's mother's role has an important function in giving strength to her daughter's testimony within the medical context. Her mother's empathy for the physical, psychological and emotional impact of her daughter's experiences also affirms a 'truth' to Lillian's own autobiographical narration of her illness experiences. This ability to narrate one's experience of illness may be weaker and less developed in children and young people. Lillian's authorial voice is reinforced by her mother in the face of the discontinuous narration of her experiences of the biomedical system and responses by some teachers (authority figures) in school. Lillian's mother brings a 'vicarious authorial voice', which formulates the thoughts, memories, experiences and intentions that the injured person cannot articulate for herself (Lars Christian Hyden, 2008).

Lillian's ability to reflect upon, and to comprehend the problem of the MUPS from more than one position seems crucial to her ability to reaffirm a positive identity despite MUPS.

As will be highlighted in the analysis of parental focus group accounts, difficulties can arise when MUPS sufferers lack emotional flexibility and linguistic manoeuvrability in the familial narration of illness.

'I don't think people were seeing me differently because I had the same close friends when I first started having these things and once I explained what was going off. I think they understood it but I think I went through a phase where I was kind of scared to meet new people because if it happened they might be shocked or upset about what happened.' (Lillian)

At the time of the focus group discussion the researcher was aware that Lillian had been given a diagnosis of non-epileptic seizures. Some illnesses continue to have a social stigma, even when diagnosed, such as epilepsy or HIV. It is quite possible that Lillian's reluctance to name the diagnosis to the group was an indication of shame associated with social stigmatisation of such a label. Furthermore, how does Lillian make sense of the prefixes such as 'non epileptic' – if these are not epileptic what are they?

Increased stigma could be attached to the idea that the doctors may have been ambiguous in the language they used to explain the diagnosis or offered only a vague explanation about the nature and origin of the symptoms. It is possible that Lillian's vagueness or fragmented 'story' of symptoms may have something in common with Julie's silences. A lack of alternative language outside the largely substantive language of biomedicine makes descriptions of the young person's bodily experiences difficult, both for healthcare professionals and in terms of the comprehension of the condition by young people and parents.

Throughout the initial period there are references from Lillian and her mother that 'things aren't right' or 'not normal', and a desire from Lillian 'to get back to normal' to be able to re-engage with her schooling and sporting activities. I understood this as a desire to return to the coherent stories of her life following the onset of such an unpredictable illness.

This also reflects upon the way healthy life narratives are generally presented in the media, in coherent ways with the dominance and vividness of concrete facts. Lillian and her mother have the memories of these coherent life stories, which are unable to give much comfort in the face of the daily fainting and seizure episodes that are dominating the life of Lillian and her family. However, it is this desire to return to the 'normal' that offers resistance to the impact of illness which can only lead to 'falling out of life' (Gadamer, 1996, p.42).

Lillian's Journey Towards a Quest Narrative of Illness

The extracts below were selected from Lillian's account of her experiences of the illness because they denote a shift in a problematic self-narrative towards an alternative Quest Narrative (Frank, 2002, p.118). In this narrative typology 'Illness is not a good thing by any means, but protagonists of quest narratives find ways to work with illness, keeping their lives moving forward'.

What we can discover in these extracts is a series of 'innovative moments' (I-moments) (Gonçalves et al., 2009). The analysis has utilised this model to identify five types of 'I-moments' of different natures and functions in the change process: action; reflection; protest, re-conceptualisation; and performing change. When studying the transcripts for I-moments it is important to bear in mind the features of the problematic self-narrative (the rule) in order to identify exceptions to this rule.

Lillian also shows a capacity for what the neurologist Goldstein (1934/1995) has described as 'abstract attitude': a person's ability to use imagination to move beyond a purely functional concrete representation of the world and self.

Researcher: What about you two? What kind of explanation did you give yourselves before the diagnosis?

Lillian: *I kinda expected to have a diagnosis about what I was having but I thought I might not get one [so I] might as well get on and don't let it stop you from doing anything. I felt what was helpful was being referred to this clinic [Paediatric Liaison] because I couldn't speak to anyone else apart from my mum about what I was going through 'cause when I was first diagnosed as 'unexplained seizures' I thought it is unusual – no-one else like me sort of thing – but there are other people that have either undiagnosed things or similar sort of things to me so I'm talking here about what I was going through. I used to think: 'Why is all this happening to me?' but I have got on with it now.*

In this extract we see Lillian's ability and willingness to engage and utilise reflection in external dialogue as leading to a comprehension of the problem-diagnosis from two different positions i.e. the beginnings of re-conceptualisation of the problem self-narrative with the idea that she was not unique in her experience and that there were others who had a similar unexplained diagnosis.

We can also identify a repositioning of self towards the problem; from a sense of frustration of not having a clear diagnosis and an explanation for changes to

her capacities (problem self-narrative) to more of an acceptance of living without 'knowing': 'I got used to it'. In the final sentence we see the contemplation towards action: 'pushed myself' towards performing change and 'to do other things'.

It is important to recognise that these hermeneutic changes developed over time by Lillian without other external facilitation of a therapist identifying opportunities within ambivalent 'I-moments', as envisaged in the model proposed by Gonçalves, et al. (2009)

'I think at first we stopped doing things so: "Lillian's tired, we can't do that", but I didn't want to stop people doing things, so if people wanted to do things I would just do it anyway. People also seemed to understand what I was going through...I don't want people to see my illness as stopping me to do things...I just keep going until I am pleased with myself (h)... I'm quite positive about the future I have set all my goals that anyone else would have set...if I try hard enough I think I will achieve what I want to do in the future... I've got used to not knowing what it is. I'm not too bothered if I find out or not. I would be interested to find out.' (Lillian)

In the above extract we can witness an element of protest towards the problem driven by the responses of others close to Lillian, and her own ability to consider how others might see her. The process underlying any transformation is an ability to engage dialogically with others, and to be able to draw upon resources to challenge others' perception of her problems in terms of weakness or vulnerability. Developing persistence in challenging the problem self-narrative gives Lillian some joy and a sense of achievement. Her focus here is centred upon change when she registers a sense of wellbeing as a consequence of change through a defiance of the social impact of the illness: 'I have set all my goals that anyone else would set.'

Lillian's story of 'narrative reconstruction' was unique among the focus group members who also gave examples of ambivalent 'I moments' versus a 'problem self-narrative' but to a lesser extent than Lillian and the problematic

self-narrative tended to dominate within their internal dialogues. The other young people in the group were also more sceptical about engaging in external dialogues.

As a researcher/clinician I have been wary of investing too much in the possibilities for change in the young people's stories. Any such well-intentioned pre-understandings about change or improvement with MUPS sufferers, I observed, can have an alienating impact upon the young person, who may receive such signals as not understanding or fully appreciating their experience of symptoms. This may likewise present an issue for parents stories raised in the focus groups I shall now consider.

5.1.1 Parent's Focus Group

'It is not unusual to hear parents of children who are very seriously ill talking as if they were the patient: not being able to think, feeling chaotic, developing a range of physical symptoms, losing their memory, feeling 'shell shocked', 'going to pieces'...Clearly they are sparing their child some of the impact by being in the front line of battle themselves' (Judd,1995, p.91)

Within the course of the parent group discussion many of the participants shared similar metaphors and phrases introduced by Judd to describe their experiences in parenting their sick adolescent.

Dorothy (Matthew's mother) – 'Parenting from a close distance'

Dorothy, whilst able to express concern and caring for her son Matthew's dramatically changed circumstances due to the impact of symptoms, also conveys a sense that she has a style of parenting that keeps her own feelings from her son's experience of illness:

'We kept taking him. He got stomach pain at the time and the doctor kept saying it was stress; which, I mean, you can never imagine Matthew

suffering from stress, he is a better person than I am. I mean he is so laid back, he is horizontal, just completely, he is a completely non-stressed child and always was....I think the worst thing at the end was that we started to doubt him...We sort of started to think, well, hang on, they keep saying there is nothing wrong. But it took three admissions to A&E in an ambulance for an A&E doctor to realise what was wrong: his stomach lining had gone. It took weeks to get that far, and then it was so far gone that he ended up with the virus in his muscles, which gave him the CFS/ME.'

Dorothy, like Matthew, appears to have been left 'rudderless' in the absence of a medical explanation for the cause of symptoms. Dorothy shares her feelings of doubt and perhaps guilt following the doctor attributing Matthew's symptoms to 'stress', as this contradicts her experience of her sons relaxed temperament and the intensity of pain. For Dorothy, her hypothesis is confirmed when a scan revealed that his stomach lining had been damaged, later leading to the diagnosis of CFS/ME.

Prior to the diagnosis Dorothy feelings of guilt about not believing her son, highlighted in the thematic analysis, was a common feeling expressed in parental stories which was triggered by moments of 'doubt' in relation to the authenticity of their child's symptoms. It is possible that the dominant medical and wider cultural discourses reinforced by the limits of biomedical paradigm, lead parents to associate 'doubt' with purely physical symptoms, rather than seeing the possible sources of distress in mind/body/culture as part of the holistic picture of their child's presentation.

Dorothy gives a vivid and quite dramatic account of Matthew's sleep and eating problems.

'But once this was diagnosed they were very good...the physiotherapist continued straight away but he couldn't get upstairs. He has got a loft bed, so at his worst he couldn't climb the ladder to his bed – we bought a recliner actually (h) one of the big ones...but it was just hard work; he couldn't eat because his stomach was so bad...he was breathing in the acid

because of the acid reflux...so if he lay down he couldn't breathe. So he slept sitting up a lot of the time which meant he was awake all night. He was very good, he didn't wake us particularly, he used to sit up and get on with things.

In the images Dorothy gives of Matthew's waking nights she recalls her son's stoical response to the trials that illness has brought into his life. The manner in which Matthew manages pain and extreme discomfort, including sleeplessness, is positively connoted by Dorothy: 'He was very good, he didn't wake us, he used to sit up and get on with things'. This seems to suggest that individual stoical self-sufficiency in the face of illness and its related disturbance is valued in this family. It is possible that Mathew's approach to managing his symptoms mirrors his father's attitude to living with MS. His father's experience of long-term chronic illness may have shaped family attitudes along the lines of 'Don't let it (illness) beat you: soldier on as long as possible to retain your independence'.

Although I gained a sense of emotional concern, care and respect for individual family members personal integrity from the analysis of Dorothy's and Matthew's accounts, it is possible the family's belief in the individual's ability to rationalise their personal dilemmas reduced the potential for dialogue between family members about troubling emotional issues. As Dorothy's story unfolds we can see the ways in which pragmatic aspects of illness impact on daily routines and is an explicit part of the family culture.

'The physical effects we dealt with: we were lucky we home educated him; he didn't have a school to cope with...we just geared his education to his energy level. We weren't limited by him having to study for exams and he didn't take any. ...the physical things, he could still walk, he used a cane for four years because of the weakness in his legs, the muscle weakness... Getting the medical professionals to listen to parents I think is a huge problem. It wasn't until one doctor realised, put all the symptoms together and said: "Wait a minute it is this" and then everyone said, "Oh yes". How

bad do you get before they do something? ...It is five years on and he is still tired. He has done brilliantly, I mean he did one year at college last year and he is at university this year, he is fine...but he is tired.' (Dorothy)

Dorothy expresses a view that we are 'programmed' to believe the expertise and knowledge of medical professionals and that young people and their parents put their faith in medicine as an institution. Dorothy's faith in doctors is undermined when Matthew's illness experiences are dismissed by doctors who are no longer 'listening to parents' There is a critique of large institutions implicitly suggested in Dorothy's accounts: 'We weren't limited by him having to study for exams' indicating that home education provided the family to provide him with appropriate physical care and neither prevent Matthew gaining access to university-level education.

Dorothy is left wondering if they hadn't found a diagnosis how long it would have gone on for and how bad it would have become, despite the treatments post-diagnosis were largely non medical. From Dorothy and Matthew's perspective their feeling of rejection by the medical system reinforced a further withdrawal from relationships with institutions, reinforcing their familial beliefs on the need for self reliance but also reducing the possibility of reducing their access to different perspectives on MUPS from mind/ body/culture theories about the sources of distress attached to the condition.

Martin and Carol – Stories of Parental Resistance

Frank (2010, p.118) suggests that the chaos narrative, the second of his illness typologies, is anti-narrative 'because one thing does not lead to another' neither is there 'much of a plot as the protagonist/s are stuck with an immovable complex of obstacles, including untreatable medical problems, financial and family problems...blocking movement to any kind of meaningful response'.

What emerged perhaps most vividly from the analysis of the married parents of Andrea, Martin and Carol's accounts of their experience, was that some parents

– perhaps more than the young people themselves – are not passive recipients to the endless stream of obstacles within a chaos narrative. Carol and Martin’s energies and purpose is to convince healthcare professionals that their daughter Andrea should be treated like any other sick young person in biomedicine’s restitutive narrative, within which ‘one thing does indeed lead to another’.

Carol and Martin continue to strive through protest and personal sacrifice for their daughter and her family to be recognised within a restitution narrative. In a restitutive plot, their daughter Andrea became sick, is diagnosed and treated by medical doctors and healthcare professionals and as a result has some measure of health restored. This is the only plotline, which has a semblance of normality and meaning to them.

According to Carol’s account of the initial appointment and opinion of the doctors, they were dismissive in the face of Andrea’s deteriorating symptoms. Woven into their accounts are counter-stories to doctors’ reported views that because no organic cause was found then it must be psychological, or to do with school avoidance. In the Focus Group it was important for Carl and Martin to tell their account which was presented in the form of a lengthy monologue. I felt Carol needed to ventilate this very first order factual account to a sympathetic audience in order to restore some credibility to Andrea and the family’s experience. I thought it would be important for the reader to get a sense of the whole text, but due to space I have included most of the account in the Appendix 8.

‘I’m Carol (tearful 8.5) and I’m Andrea’s Mum she’s a (1.5) she’s 15. About two years ago she had gastroenteritis that’s how it started (.) I can remember for five months she was just laying on the settee, she’s missed about 18 months of school and (1) she’s been diagnosed with CFS/ME but...I think it would be best if I told you our full story.’ (Carol)

‘Andrea had – no we – had trouble getting into the next hospital because Andrea hated those doctors because they never helped her. All they’d do is

give her tablets and they didn't believe her: she'd sit there crying and they didn't "believe her" and some of them were so patronising to her but then Dr. C, she loved going to see him and we walked right in there and he said, 'Right Andrea we need a picture of your tummy'. He treated her as a grown-up, showed her all that he was gonna do and she cried. And she was sobbing because he wanted to help her and he believed her, and she, well we couldn't believe it [To Martin: relief wasn't it?] it was relief and we put him on a pedestal because he's a wonderful man.' (Carol)

'I mean we saw a clinical psychologist and he was wonderful...he loved Andrea. He said, "If all my children were like you", he said you can come and counsel with me and he said we are abnormal because we're very close, but he said, "I can't do anything for you there; nothing wrong with her".' (Carol)

"There's no way Andrea doesn't want to go to school" because that was his brief, to tell school she doesn't want to go to school.' (Martin)

This point followed on from Carol's and seemed to counterpoint the perception of an inference from doctors that school avoidance could be psychological.

'It sounds like Andrea: she's always had so much determination as well and she's known all along she's really ill and she's had low points. I've always believed in her because she'd try anything wouldn't she? Anything. They said she would try (.) even now, and I mention things to her (1) "Shall I have a go at that mum?" (.) 'Well I'll put this to you, you don't have to do it'. "No I will, then if they don't work I won't do it".' (Carol)

Carol and Martin attended both focus groups and explained that they believed that it was important to participate in such groups to help others who in the future may feel isolated and distressed by similar experiences to their daughter and her family.

The tears as Carol introduced herself may have been triggered by the nervous energy involved in having the opportunity to share the story of her daughter's and the family's experiences with a willing and sympathetic audience; some of whose members may have things in common with their own experiences. Presumably many medical, educational, and indeed family contexts for telling their story have been self-enclosed environments whereby only restricted stories are offered.

Despite Carol's often lengthy monologues, both she and Martin were vocal yet respectful listeners within the group discussions. Martin, occasionally interceded to offer additional information, endorse, or clarify Carol's remarks. The accounts are often very literal with descriptions of responses, assessments and treatments offered by doctors. The accounts of relationships with medical establishment are monological and univocal, and I found it sometimes difficult to maintain concentration of the 'factual' record in Carol's recounting of events.

Frank (2010, p.90) has commented 'stories are not the best medium for telling what might be called definitive truth or singular truth'. I think here he is referring to the way in which our memories and perceptions often deceive us and sometimes truth stories refer to desires about what might have happened rather than what actually occurred. However hard to follow, I believe there was a truth in the telling of Carol's story, which included a lot of worry and concern about her daughter's physical condition which then developed into anger and protest to preserve her and the family's integrity. For Carol and Martin the truth story was possibly a search for meaning in their experiences, and whilst I sometimes found it hard to concentrate on the accounts, the other parents in the group were very engaged and connected with these accounts.

After the group, I commented in my Research Diary, 'I am beginning to feel what is meaningful to me as a post-modern researcher and what might be meaningful to the experience of young people, parents and healthcare professionals is different. The parents' group was successful in allowing parents to put some coherence around their experiences in an atmosphere that permitted them to speak freely, but some of the stories are univocal and

delivered with definitive truth, or with a notion that the truth of the story will be told when they get recognition from the right person in the medical institution'. A quote, though not definitive that has helped me to think about difference in meaning and the dilemma it presents is:

'What counts is not fixing meaning in some propositional content, but rather to understand meaning as an on-going process of re-telling, with attendant effects on different occasions of telling' (Frank, 2010, p.92). However, parents, young people, and professionals are surrounded by a culture which searches for fixed meanings in propositions.

There are clearly 'Heroes and Villains' within Carol's story, as represented by doctors and health professionals. Villains are the doctors who are perceived as disbelieving, disinterested, unsympathetic and lacking in professional thoroughness. The heroes are those doctors who have been perceived as taking Andrea's symptoms seriously, who are professionally meticulous in terms of their approach to the investigation and in their medical treatment of the symptoms.

The characters in Carol and Martin's story have subject positions and are also cast in roles in which they can be 'positioned' or 'position'. For example, when Andrea's authenticity is questioned by unsympathetic and disbelieving professionals it triggers a determined response from Carol and Martin, who may also intensely feel the incredulity of their daughter's experience with pain and illness.

Carol and Martin's *raison d'être* therefore is to repair this affront to Andrea's identity and their integrity as parents. Carol and Martin's accounts reminded me of Hilde Lindemann Nelson's (2001) definition of 'master narratives' which are often archetypal; consisting of stock plots, and readily recognised types utilised to make sense of our experience and to justify what we do.

Carol and Martin's stories suggest they utilise accounts of the 'good' doctor and the assessment of the psychologist to highlight and compose a counter-story

aimed at resisting and repairing Andrea's identity. There are a number of comments that the physical symptoms cannot be as a consequence of her mental or emotional capacities, and the psychologist's view confirmed this.

Martin's brief comments about the meetings with the psychologist are guarded, and probably intended to encourage the audience to understand that Andrea wasn't seeing because of a 'mental diagnosis'. I did however, sense an apprehension in the couple, perhaps based upon perception that a psychological explanation for the symptoms may attract "stigma" to Andrea's problems, based upon others' assumptions that there may be a problem with her development or relationships at home. These perceptions are reinforced by Western cultures' emphasis upon the dualistic split between mind and body, and negative connotations attached to psychological breakdown or mental illness.

There are many examples of Andrea's emotional responses to health practitioners which are highlighted and utilised by her parents, and used as a barometer with which to either endorse or renounce professional qualities or deficits.

What is also striking is Carol's sensitivity towards her daughter's painful symptoms. She describes how she is unable to rest and thinks she is going 'mad'. She feels she had to continue to push to get a diagnosis and asserts that 'the right people are out there if you can find them'.

'Andrea has got a mentor who she can't stand and this mentor is a Senco, who doesn't put things in place as she should, so I have to ring her and her secretary said, "Why doesn't she do that?" and I say "I don't know", but I would, and then today, because Andrea is falling behind on her maths she's now offered this.' (Carol)

Carol and Martin's accounts frequently involved a story of an 'adversarial dance' between themselves and medical and education professionals/institutions. The metaphors within the accounts are associated with conflict, 'fight'. At one point,

on receiving a new piece of information, Carol reports, 'It was like a slap on the face'. In this sense there are many aspects of the speech acts that were performative narrative (Judith Butler, 1990). The language continuously 'fixates' and 'isolates', breaking continuity in awareness or mindfulness. However, behind the public dance Carol and Martin also spoke about their worries, uncertainties, sacrifices and fears for Andrea and the family within the privacy of home.

Louise – Stories of Ambivalence and Alterity

It has been suggested that parents with children and young people who experience MUPS have difficulties in engaging in psychological or emotional talk. The controversial term alexithymia was coined by Sifneos (1972) and its features include difficulties in describing or differentiating emotions, a tendency to somatise distress, externally oriented thinking and impoverished fantasy life. (Erskine and Judd, 1995).

Louise is not a parent who fits the label of alexithymia. She presented with both self and relational reflexivity when describing her experiences of parenting an adolescent with MUPS. She was able to consider the other side of people's stories and willingly shared her doubts and ambivalences about her life and the family's experiences of MUPS.

'Becky has been to seeing a psychiatrist because she's actually got a mental illness on top of her ME, but she's actually coming out of that now... I wouldn't dismiss psychiatric help at all, I think ME can be helped; a lot of pains can be helped, because I don't think there is a difference, "its just psychiatric or physical".[general agreement from the group] I think those things work together all the time... I object to your pain is going to hurt you as much just because its been triggered[cough] by some sort of mental process it doesn't mean it's not real. and when people say "oh, its psychiatric" they're saying, therefore you're making it up, it's imaginary. I really object to that.' (Louise)

Louise's point about the importance of not seeing illness purely in terms of binary language; 'it's not physical therefore it must be psychological', was unique within the focus groups, in that she was prepared to make this explicit on the basis of her daughter recovering from anorexia. Her point about pain being equally real if triggered by mental or physical processes resonated with the group, who prior to her comment had emphasised the physical aspects of their child's problems. There was a mimetic effect in the group after this disclosure and Louise's moral position over the mind and body source of pain. Louise's comments appeared to help others begin to speak more openly about their feelings of doubt and uncertainty related to their child's condition:

'I think it does knock your confidence as a parent really because it throws you into two minds all the time whereas before when a child's well its kind of straightforward isn't it you have to make decisions and sometimes they are hard decisions but they are never as hard as when you're actually not you don't know what's the best thing for your child anymore'. (Louise)

Louise's accounts include a number of examples of ambivalence and critical self analysis (self-reflexivity) which belies a stereotypical presentation of parents of MUPS sufferers. From a dialogical perspective, Brinegar et al. (2006, p.170) apply the metaphor 'rapid crossfire' to describe the fluctuation between two overt expressions of contradictory internal voices, which seem to fight for the possession of the floor.

This cyclical movement between internal voices was also present within Carol's account, albeit the voice of self-doubt or feelings of guilt had been more concealed and the internal voice of injustice related to professionals' responses to Andrea's illness had dominated her story:

'I feel guilty that I was forcing her to do things and she really was in, she was in pain. Even though I knew Andrea deep down, I would have two arguments going on in my head: I can see she's in pain, she can feel pain; and then you think, could she be imagining it? – because you've got professional people telling you different things.' (Carol)

I thought the above disclosure was brave given her previous stance of protest. There may be a fear that to allow more attention to the other internal voice would expose her to distressing feelings or self-doubt and weaken her internal narrative which involves struggle and resolve towards external forces.

Louise's comments suggest that she is listening to both her internal voices; which lead her towards movement of thought to engage in joint action or actions to review these voices and as a consequence lead her to expand her horizons about the circumstances and see beyond the problematic narrative. Louise's account includes descriptions of the limitations of the education and medical professionals, however she does not lose her quality of reflexivity about her part in the story within her critique of others:

'You do feel like you have to do a lot of educating people and explaining, and I don't think I did enough of that at the beginning when Becky was first ill. I do think the more you can tell people about it so they got an idea... You have to learn to play the game don't you? [general agreement from group], you have to learn what the game is and how to go and get through it so how to get to (.) When I started if there was a problem you just go to your G.P. and now you, you've got to be much more assertive and say "I want you to write me a letter to this consultant".' (Louise)

'I get the feeling that people aren't really believing what I'm saying um, (.) and that makes it really quite difficult doesn't it? Well if you come across somebody who, you know, they understand and they will believe what you're saying, it's such a relief that you feel, you know, they are going to accept where your child's at, and where you're at without having to go into lots of detail.' (Louise)

Louise's presentation included a quality less apparent in the other parental accounts: Alterity, according to Levinas (2001) is a highly moral human position, which does not depend upon personal attributes or individual choices. It is the recognition of the 'other' and 'otherness' without pre-conditions. These are

difficult positions for parents of adolescents with MUPS who may be 'positioned' by cultural or institutional stories to protect and strengthen attachments against the subtle and overt ways in which their own and child's integrity is undermined. Louise's comments about her daughter's experience of pain are striking for the profound respect for her daughter's otherness, and an unfinalisability of their relationship.

'I think you can be in pain for so long that your brain doesn't know the pain is getting less and it doesn't know when it's stopping (.) I think that's what happened to Becky (1) you continually feel it (6)... It's so difficult though, because you can never know can you? [you] can't feel anybody else's pain [group responds with 'NO'] so you are never in that position when you can know what it's like or what they're feeling, or how painful it is or um, (1) I think that's why it's so difficult.' (Louise)

'The one about the wider society, if you feel like the medical profession isn't really understanding then how can you expect any of the wider society to understand either? I think you are met with some disbelief or some questioning, you know, 'Are you causing the problem yourself?' 'Is it you as a family doing this?' You're just met all the time with that disbelief I think until there is better understanding by the professionals themselves then you can't expect anyone else to understand...you see very little in the media that would educate people.' (Louise)

The above extracts illustrate to my mind how hard some parents are thinking and working in terms of responding to outside cultural prejudices whilst at the same time trying to maintain some semblance of normality and understanding within the family. Louise presents herself as a protective shield for outside prejudices about her child's condition. Clearly she has internal resources which allow her to be able to respond perhaps more flexibly to the lack of recognition of her daughter and the family's distress arising from the condition; both from institutions and wider society. I was left with a feeling of despondency about the point that Louise makes about professionals needing to change first, before prejudices in wider society are faced.

As Frank (2003) points out, health and illness invite judgements and these judgements can quickly turn into blame, disbelief, self-blame and guilt. I suppose Louise's hope is that professionals will suspend judgements and just allow the suffering and distress to become visible; therefore inviting a more empathic response from the professional network.

5.1.2 Medical Staff Focus Groups

By the time I held the third focus group with medical staff I had decided to be less structured and active in my research questioning, as I was desirous that group participants dictated the course of the conversation and hopeful that they would offer prompts to each other to offer contingency and meaning to their experience of working with MUPS. In my preamble to the first group in clarifying the research interest I used the words 'experience' and 'challenge' involved in working with MUPS.

I regretted the choice of the word 'challenge' as it conveys an assumption that the experience will involve problems or obstacles. The use of the word 'challenge' also reflected an assumption on my part that doctors and healthcare professionals would routinely find MUPS patients difficult to manage.

5.1.3 Community Paediatrician

Dr. D is a Community Paediatrician with extensive experience who is clearly very knowledgeable. He was the first to speak in the first doctors' Focus Group, which was attended by another female community paediatrician, a female child psychiatrist and a male SPR in child and adolescent psychiatry. Dr. D delivered most of what felt like a monologue mainly looking at me, as I had introduced the notion of challenge as part of 'unpacking' a doctor's experience of MUPS, which clearly triggered a lot of thoughts. I have shortened the extract, but hope the reader will get a sense the manner of his speech as well as the content:

'From my point of view there is a challenge of working with the families themselves, and families are broken into the parents and the young person. Then there is the challenge of working with the institution the young person is part of: be they health; or be they education; social services; and trying to decide how to work effectively with each of these bodies – because clearly you are trying to deal with perceptions as well as the illness. Perceptions are variables across all of these bodies, so unlike cancer, which is clearly defined and easily understood in many respects. In our British culture there is a cultural expectation that if you are ill and are defined as being ill what will follow is an acceptable perception across all these agencies as there is a consensus about the diagnosis, but with these types of more difficult illnesses it's much harder: you are dealing with perceptions which offers a clear comparison [the] one hand might be spectrum institutions who sometimes understand the child as a malingerer or a young person who is not pulling their weight.' (Dr. D)

Dr. D opens the discussion with a fluent and systemic analysis of what needs to be considered or 'be held in mind' when engaging with families with MUPS. Within Dr. D's opening monologue we can see that he is trying to make sense of what is happening for young people and their families; using a broad lens. He offers a clear comparison between the cultural profile of a clearly-defined illness such as cancer a disease which once diagnosed gives it a recognisable profile and 'end point' presumably of treatment for people to work towards. Dr. D contrasts this with MUPS, in which young people and their parents do not have a plotline, so causes are subject to speculation from a range of perceptions across institutions. The statement: 'You are dealing with perceptions' in multiple contexts suggests an appreciation of the complexity of experience for MUPS sufferers and their parents, when dealing with a range of agencies who may hold differing assumptions about the causes of the condition. This includes the notion that the young person may be malingering.

Dr. D's analysis of MUPS suggested he was speaking from the perspective of an 'expert position'. The manner in which he imparted his knowledge on the

topic was at times almost like a lecture. My moderator colleague commented after the Focus Group that she thought it was an “excellent analysis”. I reflected that Dr. D’s contributions were a good example of a doctor trained to use critical thinking in deductive methods to discover an ‘objective truth’.

In my analysis of Dr. D’s texts I had to question if I was reading the transcript with a post-modern bias. Dr. D shares his ideas in very good faith and indeed there were very few moments which involved co-constructed ideas about topics under discussion in either of the focus groups. DNA asks what is missing from the stories that people bring: I thought there may have been reference from Dr. D about his ‘subjective’ experiences with MUPS sufferers. Did he experience moments when he felt pressured, anxious or uncertain about how to go with his patients? What did MUPS sufferers trigger in him? What part does he see he plays in the process?

‘I found that there are often distortions in clinical impressions as well because of the emotional loading: there is often a lot of anger on the part of either the parent or young person, or frustration that they haven’t accessed services that are inaccessible from their perspective; there are theoretically services available for the young person in terms of education or health, but they feel they have never been delivered in an appropriate way. Building on what Dr. L was talking about either because the services are configured to deal with these types of chronic, more emotional health issues whereas they might have been if you had physical problems.’ (Dr. D)

I read this excerpt with some interest as Dr. D describes ‘emotional loading’ – frustration and anger experienced by young people – and their families as factors which can ‘distort’ clinical impressions. Dr. D reasons that the families of MUPS sufferers are frustrated (emotions) because they are split between emotional/mental health and physical health, and both are perceived as inappropriate or not accessible. Dr. D’s accounts show thoughtful objective and systemic awareness of the experiences of the MUPS population.

Dr. D attempts to unpick the 'anger' in terms of understanding the perspectives of parents, but it is possible he is constrained by time and a professional script that sees strong emotions as distorting or clouding clinical judgement and reason; rather than appreciating more hermeneutic meanings behind the patient's emotions.

Dr. D's modernist training and practice may mean there is an emotional and cognitive space between doctor and patient. In her autobiography, the physician Lori Alford (1999) writes that she had to 'unlearn' much of her medical training because she recognised it distanced her from her patients. 'Physicians can do the directing, talking at their patients. The listening on the part of the physician is becoming lost' (1999, p.2). I do not think that Dr. D is not listening to his patients, rather whether his clearly advanced medical training and knowledge which profiles deductive reasoning has shortcomings which make it more difficult to connect with the more imprecise language of experiences as presented by MUPS sufferers and their parents.

5.1.4 Child and Adolescent Psychiatrists

Two consultant child and adolescent psychiatrists participated in the Focus Groups, one in either group. The psychiatrists have extensive experience of working with children, young people and their families with severe MUPS. Dr. M is based in a CAMHS PLS in a hospital and Dr. S leads a CAMHS PLS in the community services. In contrast to the paediatricians' accounts which focussed heavily towards clinical management of young people and families with MUPS, the two – probably atypical – psychiatrists spoke at times passionately about their work, and views about how young people and their families comprehend and negotiate in the complex interfaces with medical, educational and cultural institutions.

Child and Adolescent Psychiatry is a very small world, and Paediatric Liaison Services even smaller, so it won't be a surprise to the reader that both doctors are known to myself and have been work colleagues. I have given a lot of

thought and have been party to discussions with my moderator colleague, Clare, about the issue of conducting research with participants who are known to the researcher. We concluded that the manner in which we approached the positions of researchers within the Focus Group was crucial. It would be important through our verbal and non-verbal behaviour to stay close to the researcher position of impartial curiosity. Furthermore, I would also raise the issue verbally in the preface to the Focus Group (Clare and myself knew all the doctor participants to a varying degree) and suggest for the duration of the group, we and other members would try to set aside any pre-knowledge of professional relationships in the interests of maintaining a neutrality and authenticity in the research process. The feedback from all the doctors was positive in respect of this statement. Clare and I would remain alert as to whether we were maintaining our stated positions in the post-focus group reflections.

Dr. M clearly is very passionate about the approach she has developed in PLS over a number of years. Speaking to an audience of her paediatric colleagues she constructs a collection of stories about her work and ideas in engaging and offering therapeutic guidance to MUPS sufferers and their families.

I wonder if Dr. M's talk became didactic in the sense there were some paediatricians who were new to the hospital and may not have been acquainted with her approach, but also longstanding colleagues may not have had the full story of her philosophy and approach to MUPS sufferers. I have selected by way of an illustration extracts in which she describes the process of engagement, and how she emphasises doctors have to depart from their traditional roles and take up deep listening roles and collaborative positions. There are other lengthy extracts in which she raises issues of training, setting up services based around the young person and family, differential diagnosis at an early stage rather than diagnosis by exclusion, and MUPS in those who already have a diagnosis such as cancer, Crohn's disease or diabetes.

'I mean from my personal perspective, in terms of working with the families it is about learning to be with them and learning to change the role as a

doctor. Because as a doctor you are expected to make people better, to give them advice, to do investigations, look for medicines and so forth, but really it is about much more collaborative work. It is almost like you have to pace the psychological intervention the way you pace the medical, the physical problems really; because if you intervene too quickly you lose the family, if you intervene too slow it is not right either. So it is sort of like you have to continuously review what you are doing session-to-session really.'
(Dr. M)

What came across in my analysis of Dr. M's stories (which is much less visible in the paediatricians' accounts) was a 'witness' way of speaking as well as the 'aboutness' when describing young people and their families with MUPS, particularly when considering her connections in therapeutic sessions.

What is Dr. M trying to achieve through her 'talk'? It appeared that she was strongly trying to convey a message of the utility and breadth of the approach with MUPS that she has developed over a number of years. In some ways these are homological texts; but in other ways there are representations of 'other voices' of patients and non-medical professionals within the scripts. What is at stake for Dr. M in joining the dialogue within the group is to gain a recognition from her paediatric colleagues with regard to what has been achieved by her team with an often challenging and therefore neglected group of patients.

I wondered if Dr. M was drawn to working with MUPS sufferers because they occupy a marginal liminal space, which parallels the PLS Service. This too occupies a liminal space between mental and physical health institutions which has the potential for the service to be marginalised and its members having to deal with uncertainty and insecurities about their future existence.

In Dr. M's accounts of her work with MUPS sufferers I felt there were resonances with David Hilfiker's autobiographical story of a physician who dropped out of a traditional career path in medicine in Minnesota to work with the poor in Washington.

'There is no [Medical School] curriculum for poverty medicine: no one teaches 'The Art of Medical Decision Making with Limited Funds' or Medical Compromise with Cultural Strictures. Medical practice in the community of the poor often seems a solitary speciality without research, common cause or shared experience' (David Hilfiker, 1994 p.213).

The issue for wider society is that poverty like MUPS will not go away.

'I think, as a psychiatrist, for me the most difficult thing is to continuously work in an integrated way and really work the line between medical and psychiatric...to hold the tension between physical and medical, adopting a both/and rather than an either/or position: it is very difficult even for people who have an explanation; they would come back and say well is it psychological?...I think that the progress is very slow, it is not as rewarding work as it could be with the other patients if reward is measured by how quickly you make people better. I think the reward is measured by how much you prevent disability and how much you engage the family, help them to progress, but it is very different to other families you see.' (Dr. M)

'They say they want to get better, but then its sort of the dialogue: "I have done all this but I am not getting better? What are you going to do to make me get better?" They don't come and say, "Yes I will try this, I will try that", "Oh I have tried everything and nothing works". So you have to go over and over the same things so there is learning to be with a family, and how you define problems is very important from the sort of psychiatry psycho/social type of work really.' (Dr. M)

Dr. S holds a similar position in terms of trying to run a Service with a limited profile in the wider context of CAMHS.

'My daughter has had two episodes, one with abdominal pain. We went to [the] G.P. and got into an emergency department and my daughter was examined, palpated very deeply – started smiling; we went home. After that it was

something like 1 o'clock in the morning. I thought it was acute pancreatitis. The second one was when she had a couple days at school when she had to go to the toilet for a wee every two or three minutes in the class, so she was obviously terribly anxious and getting bullied... It is interesting, because if we look at [one in ten may have some experience of MUPS in their childhood] it is really common isn't it? I think one of the ways we work is that we physically express ourselves, maybe because I think in the past when we talk about histrionic as being hysterical, you know all these quite pejorative terms...I think it is that it does take a time. You got the impression that a lot of families keep on presenting to different teams over many, many years: they had probably enormous amounts of time during that period but not necessarily being able to speak in a way it suits to help them, or to move them forward. And then again of course we are talking in a health economy where it's all about through-put and so many sessions.' (Dr. S)

Dr. S was the only doctor who volunteered a story in response to a question about a personal experience of MUPS, which may say something about medical training and practice reluctance to mix the personal with the professional. She was able to tell the story of her child and give us a picture of the natural anxiety that parents feel when their child has feelings of sickness. Dr. S appeared able to move easily into the world beyond her professional boundaries. I thought she was brave in sharing her story about her daughter, and indicated a humanism, which suggests she is capable of showing vulnerability, doubt, and is not afraid to 'not know'.

Dr. S was able to move from the general to the specific, out of which came an important connection for me as a listener. Dr. S pointed to a basic human reaction to express distress through our bodies; she also recognised that it was from judgments in her own profession that pejorative terms like 'hysteria' had made this natural expression inappropriate or somehow improper.

She is dismissive of labels like 'hysteria' introduced by her own profession. Unlike psychotherapists, exploration of the personal professional self is less evident in the medical professions and yet working with those with illness, pain,

and idiopathic pain undoubtedly requires empathy and imagination in order to connect to the experience of others. Finally, she encapsulates another wisdom about 'time' in relation to MUPS sufferers who she sees take up vast amounts of time in medical appointments, yet does not see the biomedical context and time as being hospitable for MUPS sufferers to 'speak in a way that suits them'.

What is present in both psychiatrists' stories is the ability to be reflexive about the core traditions in psychiatry and to highlight that this group of patients require the kind of understanding and emotional postures from professionals that lies outside the purview of traditional biomedicine. Not unlike the MUPS sufferers themselves, they work in a liminal space between the medical establishment and the patients life-world, and each has found ways to manoeuvre into different positions to make this possible.

5.2 Some thoughts on the benefits of DNA in qualitative research

I believe that DNA will allow the reader to gain a sense of the differing voices of young people, their parents and healthcare professionals. It reveals how young people and their parents in their private moments and inner conversations are struggling to put stories together that restore meaning to their lives, given the impact of MUPS and the problems in the external institutional world in recognising and legitimising the distress. DNA discovers how dominant narrative templates and deeply embedded professional modernist discourses and discursive practices can make hard-working health professionals 'blind' to the distress of MUPS sufferers. In this sense, DNA can ask questions of the processes involved in a healthcare professionals' single voice to locate meanings and to listen for other voices and genres from training protocols to science teachers, that may influence their outer dialogue and positions with respect to MUPS suffers and their families.

The stories and accounts from the public domain and interface between MUPS sufferers and their parents with health and education professionals are prone to stories of 'finalising' and 'fixing' in the language of 'aboutness' from all the

actors that form the human drama of MUPS. Privately there are moments of humanity and 'witness' thinking but the shortcomings of our modernist language and culture, are exposed when faced with a condition of doubt like MUPS. The strength of DNA (and there may be methodological weaknesses) is its underlying ethical commitment to bringing forth difference by revealing more and more stories and indeed metaphors to guide comfort people through difficult times.

CHAPTER SIX

6. Discussion

Dr. D: *'I think certainly with the patients I see – especially with the world-wide web – they discover there must be a cure for something, somehow, somewhere and they can read about anecdotes: they want to be inspired by these heroic stories they read about where there is a miracle cure that can be attained, and that in some sense puts some pressure on clinicians to continue investigating, whereas ordinarily they might have stopped.'*

Linda (Nurse Specialist): *'I think the hardest bit is that often, because of our experiences, we can be way ahead of the families and so we can have an acceptance of that situation, but it is how we guide them to get there when you have a family that desperately, desperately wants something that they can hang on to.'*

Matthew: *'A bit more trust would be nice, because you are young; you are a child. A lot of these professionals sort of think they know a lot more what is happening to you than you do: they are very much saying that you are not in that much pain; there is a certain lack of belief despite what you are saying. They would not necessarily, you know, believe you, [and are] a lot more inclined to think that you are mistaken, wrong or lying.'*

Dorothy (Parent): *'As a family I would say the biggest thing was the doctor who didn't believe him, didn't believe us, and just having to close down and say "No", and then you get labelled a 'fussy parent'. You are a fussy parent I noticed 'fussy parent' on his file.'*

6.1 Introduction

This Discussion Chapter will take up a number of topics emerging from the thematic and dialogical narrative analysis – topics which seem particularly striking or valuable to a systemic researcher/clinician. I begin the Chapter by presenting an overview of main themes arising from the analysis. I then reflect on the connections between the theoretical frameworks highlighted in earlier chapters of the thesis with the main themes arising from the thematic and dialogical narrative analysis.

In the rest of the Chapter I continue to explore and expand upon the theory to practice connections. I contrast the accounts of the experiences of young people, parents, and doctors in the initial medical consultation (as highlighted in the extracts above) and subsequent medical encounters. I have based my observations on the analysis of MUPS sufferers and doctors' accounts and reflect upon how fixed discursive positions and incongruent emotional postures within the interviewing process can lead to impasse between the doctor and the patient. This Discussion will also involve consideration of the limitations of Western biomedicine's approach to MUPS and how societal or cultural stories can contribute to "binds" for all participants by channelling "idioms of physical distress" through a medical/psychiatric diagnosis lenses leading towards the "medicalisation" of human suffering.

I contemplate what narrative alternatives are available to adolescents and parents who are excluded from the medical restitutive narrative (Frank, 2003) with its requisite components of emplotment and finalisability. Linking my rationale to the testimonies and illness stories of adolescents and parents I propose that their experiences have much in common with chronic illness as highlighted by the 'chaos narrative' (Frank, 2003).

I explore how MUPS sufferers' and parent accounts of the initial medical encounter reveal that they do not feel fully heard, or that their descriptions of symptoms are taken seriously. I hypothesise about reasons for mutually unsatisfying experience in the doctor/patient consultation, including the

perceptions that doctors' limited training in MUPS and pre-understandings, lead to a lack of medical/social recognition afforded to MUPS sufferers. In addition, MUPS sufferers and their families may have fears about attracting implicit labels embedded in Western culture such as 'malingering' or 'sickness as avoidance behaviour or as secondary gain'. These external narratives can combine with restricted narrative resources in adolescents and their parents which limit thought and movement in their public selves to factual/event based pre and anti-narratives (or even silence).

Adolescents and their parents often remain wedded to the idea that there is a physical 'cure' for the symptoms, which can lead them into symmetrical relationships with healthcare professionals a 'truth' about symptoms. The resulting impasse with medical professionals can leave young people and parents with a sense of alienation and social isolation, reducing the possibilities of more hopeful horizons to surface through dialogue and relationship.

I propose a model expanding the paradigmatic boundaries of the biomedical consultation by introducing concepts and practices from systemic family psychotherapy. The model introduces theory and practice for healthcare professionals aimed at styles of engagement, improved reflexivity towards doctors' positioning, and awareness of the bodily and views emotional postures in the medical encounter. The model is envisaged as a training template for healthcare professionals to introduce them to the notion that concepts and practices from modernist and post-modern paradigms can be mutually beneficial to the medical, social and emotional processes between doctor, healthcare professional, MUPS sufferers, and parents.

A focus is then given to the ways that adolescents and parents strive to develop some coherent narratives in an attempt to fill the void of meaning embedded in their experiences. Here I consider some of the differences between the front stage public and back stage private stories of the impact of social isolation and loss upon the identity of the adolescent with MUPS; how living with MUPS permeates and weighs upon relationships within the family for months and in severe cases, years, leading to disability into adulthood and the potential for

unending stagnation of family life and relationships. Young people's and parental accounts surprisingly revealed stories of doubt, confusion, uncertainty, ambivalence, anxiety, despair, hope and self-healing, which may be very different from the public/professional images of adolescents and their families and views of healthcare professionals living and working with this condition.

Based on the connections between dialogical/narrative theory and young people's, parent's and healthcare professional's stories of their experience of MUPS I observed 'innovative moments' that can accrue to produce 'proto-narratives' which point to possibilities for new positions, movement and revisions of a negative self-narrative. For example, exploring or engaging with a young person's inner dialogue to identify different actions, reflections, and protest than have been previously been attached to the problem self-narrative, can offer hope for reconceptualisation of a life beyond MUPS associated with Frank's (2003) notion of the 'quest narrative'.

I consider the contemporary role and practices within paediatric medicine and psychiatry towards MUPS in children and adolescents with MUPS. I have taken a phrase from a community paediatrician in a focus group who suggested 'MUPS is nobody's core business' as a headline for this part of the discussion.

I explore reasons why despite government and professional policy documents raising the profile of MUPS, has not been not translated into practice, particularly for children and adolescents, and why MUPS sufferers are in danger of falling between Services. I also reflect upon the analysis of the hospital and community paediatricians, child psychiatrists and other healthcare professionals and gaps in the fieldwork, particularly in relation to accessing accounts of doctors in primary care settings. I discuss the strengths, limitations, quality measures and parameters of the thesis with particular attention to the Research Method and analysis, and possibilities for alternative qualitative research approaches than can build upon this unique, yet exploratory study into the experiences of those who live and work with MUPS.

In the conclusion of the Chapter I offer suggestions regarding the benefits for healthcare professionals in accessing theoretical frameworks that will build upon their existing epistemology of knowledge and concepts of identity which I hope will broaden their skills in their practice of engagement and comprehension of MUPS sufferers and parents'/families' experience.

Overview of Main Themes Arising from the Thematic and Dialogical Narrative Analysis

The following is an overview of the main themes arising from the thematic and dialogical narrative analysis (DNA) abstracted from the focus group accounts of MUPS sufferers, parents, doctors, healthcare professionals.

- Descriptions of the initial medical consultations in young people's and parental accounts conveyed a sense of deeply unsatisfying encounters in which they did not feel listened to or believed. The feeling of not being listened to or understood by a doctor or healthcare professional left the young people and their parents unsure as to what, and whom they could trust outside of the family. Young people's and parents' accounts suggested they saw the doctors' non-diagnosis of their child's symptoms as a rejection and a source of frustration and sometimes anguish, as it undermined the authenticity of the young person and family.
- Parental accounts of their experience of living with their child's MUPS suggest they quickly move into an advocacy role in their relationships with doctors and healthcare professionals following the non-diagnosing of their child's symptoms. This role may be reinforced for a number of reasons; for example the perception by a parent that refusal to diagnose their child's symptoms exempts their child and family from the cultural legitimacy and meaning that a diagnosis offers. A non-diagnosis leaves their child's distress without a cure or healing, and undermines their child's honesty in their presentation of symptoms. Parents also

reported that their child does not have the language or skills to adequately convey their distress to an authoritative doctor.

Young people, parents, doctors and healthcare professional accounts all included fluctuating 'I-positions', a term from dialogical theory that refers to different and competing positions or voices of the self in both internal and external dialogues. These 'I' positions represented the difference in stances of young people, parents and healthcare professionals in public and private domains. For example, inner dialogues of parents included descriptions of ambivalent conversations about doubts versus certainty in respect of their child's symptoms. Underpinning these different positions some parents shared feelings of responsibility, guilt, love, and sacrifice in their accounts from their private world and positions of certainty and unyielding determination to secure the 'truth' about the physical causes for their child's symptoms in the public domain. These contrasting positions between the private and public positions in young people and parents cast doubt about the appropriateness of applying the blanket definition of alexithymia to young people and their families who live with MUPS. This definition suggests that MUPS sufferers and their families avoid emotionally close relationships, or if they do form relationships these are described as 'superficial' with limited differentiation between self and others, and with a language that is limited to describing their lives in purely pragmatic ways. (Vanheule S., et al., 2007; Blaunstein, J. P., 1998)

On the whole the focus group accounts revealed 'fixed positions' over 'truth stories' when in medical, educational and social domains. These positions were particularly evident in some parents' and doctors' descriptions of medical encounters, or between parents and teachers in meetings about a young person's long-term absence from school. Parental accounts suggest that they try to restore the loss of credibility on behalf of their child following a doctor's decision not to diagnose. Some parents assume an 'vicarious authorial voice' (Hyden, et al., 1998). When immersed in the advocacy role parent language drew upon metaphors of battle, such as 'fight' or win/lose with doctors to discover a physical cause for their child's symptoms. The resolute certainty with which some parents delivered their stories about the failures of medical and

educational professionals and systems reflected an increasing social isolation and the need to restore the integrity of their child and family.

The other important character in these medical scenes involving conflict to secure 'truth' is biomedicine itself through its epic traditions and assurances offered by the restitution narrative (Foucault, 1973, Frank, 2010). For young people and parents medicine is the only cultural story available to them when presented with physical symptoms and distress in their child. As one parent commented, "We are 'programmed' to believe the expertise and knowledge of medical professionals and we put faith in medicine as an institution". Parents' accounts also suggested the absence of the legitimisation of a diagnosis created problems for young people and parents in the school context. They described conversations with teachers and educational support workers where they were questioned implicitly, and on occasions explicitly about the authenticity of the young person's symptoms.

Doctors' accounts suggest that when faced with young people and parents with MUPS they feel ambivalence and uncertainty about when to stop investigations in the face of a young person's persistent intense pain and distress. Experienced doctors may feel out of their depth and short on training and time. In their accounts they expressed some anxiety about the consequences of a missed diagnosis, which may be seen as professional failure and/or subject to litigation by patients. They appreciated that the cases were complex and demand greater understanding and liaison with mental health services, physiotherapy, complimentary therapy, or alternative medicine.

The DNA of doctors' accounts suggests that few doctors had access to alternative paradigms outside of biomedicine through which to comprehend the phenomenon of MUPS. At the tertiary level of hospital settings specialist paediatricians sometimes utilised third-person information and language to draw conclusions beyond the biological, which extended into a psycho-social assessment of MUPS patients. Both the paediatricians and the psychiatrists listened carefully to the MUPS patients' accounts with (perhaps predictably) the paediatricians seeking and hearing information about the medical/physical; and

psychiatrists accustomed to working with MUPS patients exploring the phenomenological experience of MUPS sufferers and their parents.

- Young people and parents also shared stories of past and present experiences of illness and stories of illness within the family: beliefs and myths that they considered could have a bearing upon individual responses to MUPS.
- Young people described their experience of the onset of physical symptoms as a 'collapse' or 'crash'. This collapse had repercussions for their outer and inner worlds. Young people spoke about their feelings of loss, isolation and withdrawal from social and educational life. Their accounts of living with MUPS were beset with many examples of loss: loss of contact with school; loss of confidence in learning; dissolution of previously-valued academic and social goals; loss of their desire to sustain and engage in peer relationships in school and for some in family and social relationships generally.
- The young persons' accounts offered a window into their 'inner conversations, which suggested that MUPS had totally disrupted their emerging adolescent identities. The researcher gained a sense of mourning and pain about the loss of their former healthy capacities and opportunities for achievement. Following the 'collapse' the young people described feeling a void in meaning and chaos in their daily, lived experiences, resulting in a threat to their present and future identity.
- The young people also described feelings of alienation from some medical and educational practitioners, which they demonstrated through non-verbal (silence) and linguistic manoeuvres in order to avoid dialogue with others about their thoughts and feelings of living with MUPS. Some young people shared a belief that to share their physical and emotional distress, with professionals or peers, would only lead to further emotional pain and it was better to deal with things privately.

The DNA interpretation of young people's accounts suggests that some young people withdraw into their 'autonomous self and emotions' (Fredman, 2004). This withdrawal into 'a self-contained self' (portrayed by the majority of the young people) appeared to be based upon predictions about likely negative responses from others. It was this autonomous 'self' that the young people presented in external environments. However, as noted above, the accounts of their inner conversations frequently revealed chaotic thoughts and feelings with an absence of meaning about their experience.

- From young people's and parental accounts we can deduce that the withdrawal into the private territory of the family and reliance solely upon 'internal dialogue' can be attributed to a combination of internal and external forces. The young people suggested that unexplained pain or symptoms was difficult to describe, as were the feelings engendered by the conditions. This loss of confidence in external dialogues is perhaps exacerbated by the perception that professionals do not listen, or are disbelieving. However, the young people, to varying degrees, shared expressions of doubt, ambivalence and uncertainty about their experiences of living with MUPS on their accounts of their inner dialogues.
- The DNA of one young person's account showed she had narrative resources that assisted her moving forward with her life despite her condition (Frank, 2003). These resources included remaining open and taking more flexible positions towards engaging in both internal and external dialogues. Her descriptions of living with MUPS included a more hopeful narrative about her identity and future prospects, despite not having a diagnosis for frequently debilitating symptoms. She remained open to the influence of others, she shared personal thoughts about her situation which included ambivalence within her inner conversations in weighing up how much she allowed MUPS to dominate her experience against her desire, and determination to re-engage with her life world and fulfil her potential.

- The parental accounts included similar examples of moments of ambivalence, doubt and uncertainty about the nature of their child's experiences. Parents shared inner and outer conversations in their private thoughts and family relationships, which led to a questioning and heartfelt reflection of their child's symptoms and experiences. At these times they had briefly considered whether developmental, emotional and social factors may also have contributed to their child's physical presentation. These moments of doubt surfaced in the context of competing internal voices and in private rather than public contexts.
- In terms of the impact of MUPS upon family life and relationships some young people and parents described family life and plans as being 'on hold' and suspended. Holidays and outings were replaced with hospital appointments and school meetings. Domestic relationships were tailored around the young person's symptoms and health needs. Some parents spoke about a negative impact upon marital and parenting relationships.

The accounts of doctors varied according to their status and work context. The community consultant paediatricians they received limited or no training in their early careers about MUPS. Time constraints and limited access to, and resources in CAMHS services with specialist knowledge and experience, were the source of frustration.

- Comparing the descriptions of feelings experienced by doctors and healthcare professionals of their medical encounters with MUPS patients and their parents, we can see that experienced community and hospital paediatricians also spoke of being left with a sense of frustration, isolation, anxiety, ambivalence and uncertainty about how to manage their patient's on-going physical presentations, and dissatisfaction with the absence of medical evidence and opinion. This kind of 'emotion' language is not usually associated with doctors in their traditional expert medical roles, but the language is comparable with the ambivalent inner dialogues of some young people and their parents.

- Some of the experienced consultant paediatricians took into consideration non-medical influences such as family and psycho-social factors in their assessments MUPS sufferers' experience. The paediatricians generally looked towards the 'expertise' of CAMHS or psychology Services as the appropriate service to address the needs of MUPS sufferers. However, the accounts of the trainee psychiatrist and paediatrician suggest they believed training in their respective specialisms gave little theoretical or practical access in learning about how to manage MUPS patients and their families. The views of two consultant child psychiatrists in paediatric liaison in the region who worked regularly with MUPS sufferers and their families, believed their services were marginalised and under threat from cuts, as their work was not considered fundamental to the primary business of child and adolescent psychiatry.
- Specialist and generic hospital consultant paediatricians also raised these themes, but in addition considered that increasing 'specialisms' based around medical diagnosis resulted in MUPS sufferers 'falling through the net'. Doctors and healthcare professionals both raised the issue that MDT teams in hospital settings are focussed upon their specialist medical primary tasks, which disadvantage young people with MUPS. A similar trend towards specialisms that require a mental health diagnosis was noted in mainstream CAMHS by two Paediatric Liaison child psychiatrists; raising the concerns that MUPS has become 'nobody's core business'.
- Some mid-to-late career paediatricians said they had to learn about MUPS on the job; whilst some paediatricians could see that MUPS was complex and required collaboration with non-medical professionals, most restricted their consultations and management plans for MUPS within a biomedical paradigm. However, there was an awareness of that modern paediatric medicine could be technical and physically orientated. Paediatricians' language to describe MUPS patients was restricted to

psychiatric or psychological terms such as 'psychosomatic' or 'functional' disorders.

- The community and hospital paediatricians, and liaison child psychiatrists shared many interesting ideas about how to improve the care for MUPS sufferers and their families. The paediatricians spoke about the needs of patients and the dilemma of clinical management for the doctors, while the paediatric liaison child psychiatrists offered a family-focused, holistic and phenomenological view of their work with MUPS and included stories of their personal/professional 'self' in therapeutic encounters with patients.
- In both the paediatricians' and healthcare specialists' accounts the professional and institutional 'self' of the clinician appeared influential in shaping their approach to their primary tasks. Indeed, explicit and implicit narrative templates were embedded within accounts. For example, the healthcare professional had some awareness that the culture in the children's hospital can be largely focussed towards the treatment of disease and restoration of physical health. The healthcare professionals had more opportunities to respond to the more informal personal and emotional dilemmas of young people and families with MUPS than medical doctors. They are able to focus upon wellbeing questions with their patients and seek to understand MUPS sufferers' distress. Alternatively, they explained they can feel constrained from engaging in therapeutic conversations with patients by feeling caught between conforming to the physically oriented care, and involving themselves with MUPS sufferers – who can absorb time and emotional effort yet with limited improvement of symptoms or evidence of motivation towards recovery by young people.

Connecting the Theoretical Frameworks to the main themes from the Focus Group Accounts

I will now explore the connections between the theoretical frameworks reviewed in earlier chapters of the thesis and the main themes arising from the analysis of the research participants' accounts.

An important aim of this research study has been to apply the theoretical lens of post structuralism investigation of the experience of young people, parents and healthcare professionals who live and work with MUPS. However, as noted in the Literature Review, there has been some ground-breaking work in the field of chronic illness and MUPS undertaken by Systemic Family Therapists from earlier theoretical systemic traditions.

Systemic Research and Theoretical Frameworks

Campbell 1986, Fischer & Ransom (1992), Terry & Berge (1992) explored a wide range of illnesses to determine relationships between health and family structure, problem-solving abilities, illness beliefs and styles of managing emotions. Minuchin et al. (1978) introduced a new theoretical framework in researching causes of somatisation in children and young people which was distinct from the intra-psychic models that had previously dominated the field of psychosomatic medicine. His team focussed upon counterproductive family relationships and patterns that they believed explained a patient's symptoms.

Hardwick (2005) explored the myths and beliefs that families with a child with MUPS hold about illness and medical practices, which he described as 'medicalising families'. What proved to be unique about these family research/practitioners was they identified sources of distress and the opportunity for the resolution of, often intransigent, problems of unexplained symptoms in the family and social relationships. Many of these concepts were innovative in pushing the boundaries of the research and practice for MUPS

sufferers and their families beyond the parameters of the largely modernist biomedical and psychological approaches of the time.

Some of the above theoretical concepts remain relevant for this research study and connected to themes arising out of the Focus Group participants' accounts. For example, the young people's and parental accounts include references to past and present stories of illness and health generally in family relationships. These stories give credibility to Hardwick's observations that powerful stories related to the uncertainty of illness can shape patterns in relationships, which in turn influence the positions taken by (and available to) young people and their parents with unexplained and unresolved illness.

Altschuler (2012) has introduced systemic concepts for professionals who work with chronic and life threatening illness across the lifespan. She has identified loss, adjustments to loss, blame, self-blame, anxiety and guilt as features of the family's experience of living with chronic illness. These issues resonated throughout the accounts of young people, parents and healthcare professionals who live and work with MUPS sufficient for me to draw the conclusion that MUPS sufferers and their families experience parallel, in some respects, experiences of young people with diagnosed medical conditions. However, as Altschuler has noted, finding your child or adolescent ill can be highly distressing and in some situations traumatic, but then to be told that the cause is unknown and treatments do not work can bring additional anguish to parents. The idea that MUPS sufferers may blame themselves for the increased individual and family social isolation, particularly in the absence of a medical explanation, was evident in their accounts.

However, aspects of these systemic approaches resided within the structural modernist paradigm, based upon the observation that 'stories that subjects and families give about their experiences are largely discounted in favour of an expert story defined by professionals' (Griffith and Griffith, 1994, p.21).

Narrative Research and Theoretical Frameworks

Griffith and Griffith (1994) opened the field of psychosomatic study to narrative and phenomenological research and practice, which incorporated giving priority to first-person accounts of MUPS sufferers. Their approach was based upon the premise that helping patients to share suppressed 'self narratives' described as 'unspeakable dilemmas' rooted in family, social and cultural events and experiences, began the process of healing of the emotional pain represented by physical symptoms. This exploration of first-person stories also questioned the different professional 'expert' approaches that had claimed authority to declare what is real and not real about the MUPS sufferers' problems. Griffith and Griffith (1994, pp.21-22) also noted 'the particular languages that are used in each of the biological and psychological approaches draws certain aspects of a patient's experience into sharp focus while obscuring others.' The authors were also interested in the largely hidden narrative templates and processes in the dominant biomedical and psychological culture that denied the patient the opportunities to voice the phenomenological aspects of their 'lived experiences'.

This research study was inspired by the wider theoretical lens of dialogical and narrative theory evident in the work of Griffith and Griffith. It focussed upon the first-person accounts of research participants of their experience of living and working with MUPS through the theoretical lenses of the autonomous, dialogical and narrative theories of self and the multiplicity of realities as described in the socially constructed theory of knowledge.

Social Constructionist Theoretical Frameworks

Many of the participants in the focus groups will have been raised in a culture where modernist ideas dominate, especially the idea of individual autonomous 'selves' who believe the world 'exists 'out there', and that we use our brains, logic, and language to discover the 'truth' of this world.' (Campbell D., 2000, p.11). For some time social constructionist theorists have critiqued this ontological dualism of the independent mind and the outside reality of the world,

highlighting the absence of an adequate explanation to describe how the inter-subjective and the objective reality are causally linked.

The central premise of social constructionist theory is that knowledge is constructed between people. Sampsom (1985) criticises the modernist notion of the autonomous self as having freedom to act and think independently of the outside world and external influences. He postulates 'we learn who we are in relation to others, and we act as a result of many influences from the environment around us, many of which we are unaware of' (Sampsom, 1985 [in Campbell, 2000 p.15]).

Gergen (2000, p.122) has suggested social constructionism proposes: 'What we take to be knowledge of the world grows from relationship, and is embedded not within individual minds but within interpretative or communal traditions. He also suggests in advanced Western societies we distinguish 'cause and effect' in the material world or in mental life, since the mind and material world are viewed as separate. But it is far more difficult to determine how the psychological impacts upon the physical: "the questions of how "mind stuff" produces changes in the material or vice-versa remains unanswered to this day' (Gergen, 2000, p.8)

The underlying social and linguistic structures within biomedicine which predominantly emphasise the 'causes and effects' of disease and can view the 'body' in 'material' rather than in holistic terms (Lock, 1993; Foucault, 1973; Toombs, 1992). This was reflected by those in the healthcare professionals' and parents' focus groups as they described the biomedical approach to hospital care which they perceived as giving priority to physical care and treatments at the expense of attention to the emotional and psychological health of patients.

The parental and young person accounts presented a picture of clinician-dominated interactions, which were responded to by parental challenges to the doctors' authority and clinical knowledge: 'There is a cure out there but you have to push the doctors to investigate properly' and 'I often feel that I have a

better knowledge and understanding of Andrea's illness than the doctors' (Carol).

The paediatricians in this study felt their encounters with MUPS sufferers left them with ambivalent and unsettled feelings based upon the failure to discover a diagnosis or cure for the young person's distress. For some doctors the non-diagnosis of the patient left them with feelings of professional dissonance as their decision not to give a diagnosis contradicted the core purpose of their profession, which is to discover the origin of symptoms and make ill people better.

One community paediatrician commented that parental emotions, such as anger and frustration, distort their perceptions of their child's difficulties. This exemplified the belief of some paediatricians that young people's and parents' reporting of symptoms was not always precise – and this highlighted a doctor's preference for precision over ambiguity when diagnosing and treating symptoms. From the young people's perspective they often found it difficult to access the language that adequately described their internal pain and/or other symptoms, some of which were subject to regular change. These examples underscore both the shortcomings of biomedicine and the mismatch between the 'knowledge schemas' and 'frames' of clinicians and MUPS sufferers (Tannan & Wallet, 1999; Deary, 2005; Wilkinson, 2005; Engel, 2000; Griffith and Griffith, 1994).

Some parents' and doctors' 'claims to truth' about symptoms are made in the medical consulting rooms. Their positions appear to be strongly influenced by a shared belief in biomedicine's restitutive model (Frank, 2003). The belief is that medicine will accurately identify, label and treat symptoms, and by a diagnosis of exclusion, discover a single 'truth' about the cause of illness. Also embedded in the 'conflicting dramas' of the medical encounter is the modernist notion that knowledge of the illness is 'out there', with parents and doctors becoming 'competing detectives', with sometimes the consequence of distressing and dismissive conflict about the validity or mystery of symptoms despite 'all the actors sharing a deeply held concern about the ill child' (Mattingly, 2010, p.52).

From the perspective of MUPS sufferers and the parental accounts their perception of what others think about them and what they think about themselves is intrinsically connected. An example of this interconnected internal story is given by Matthew, following a late diagnosis of CFS/ME. For Matthew and his mother Dorothy the diagnosis partly represented a cultural metaphor that protects the possessor from 'what other people think'. The diagnosis also gave legitimisation to the symptoms for Matthew, who had been troubled by self-doubt, and it restored some direction and faith in his own judgement. The diagnosis meant that Matthew felt he could return to the culture of the ill or healthy, rather than remaining outside of the mores of culture altogether. However, Matthew explained the diagnosis made little difference in terms of symptoms of fatigue, biological treatment and distress in daily living. In common with other young people in the focus group, distress in his internal dialogues remained difficult to process, and continued to be dominated by problematic self-narratives.

In the young persons' and parents' focus group accounts 'truth stories' tended to dominate the discussion as parents offered accounts about their experiences within the medical and educational systems based upon arguments about the material reality of their child's physical symptoms. In these accounts parents would describe advocacy and adversarial positions in relation to medical and healthcare professionals. As Frank (2010) has pointed out 'truth stories' can be anti-narrative and are subject to 'twists' particularly when striving to establish a singular truth. Characters in the medical profession were often described in terms of 'heroes and villains', reflecting a range of perceptions of healthcare professionals including noticing their indifferent bodily signals and postures, and their negative or positive attitudes towards further investigations of symptoms. Foucault's description of discursive and regulatory practices in modernist Western institutions is useful in the microanalysis of focus group participants' accounts. Through Foucault's theoretical lens modern medicine incorporates a canonical genre described as a 'regime of truth'. MUPS sufferers' accounts expose the pervasiveness and shortcomings of medicine's restitutive narrative in comprehending and healing of MUPS sufferers' distress.

There was an assumption within the Focus Groups that sharing truth stories about these experiences would be validated by the other focus group members. Indeed, they appeared to offer some solidarity based upon shared experiences, with room for expression of differences. These processes mirrored the research of Irvine (1999), who also observed 'narrative conformity' in their focus group study of co-dependents.

However, the focus group provided a context for some young people and parents where they felt able to share individual and family external and internal dialogues in which thoughts and communications were generated from the relational 'interpretative and communal traditions' (Gergen, 2000, p.122), rather than the autonomous mind. These comments led to expressions of doubt, uncertainty, anxiety and ambivalence about individual and familial experiences. The sharing of internal dialogues precipitated a change in tone and emotional posture of the young people and parents, presenting a striking comparison in the tone and verbal delivery of the 'truth stories' when describing their experience in the medical encounter.

Hermens (2008, pp.194-195) suggests that the theory of a dialogical self which is a component of these internal and external dialogues

...can only exist on the assumption that the other person is not purely outside, but simultaneously part of the self and constitutive of it...The self can be properly understood only when social interchange and intersubjectivity are considered as intrinsic to its nature. (Hermans, 2008, pp.194-195)

Dialogical theorists (Hermens, Kempen and Van Loon, 1992) have defined the autonomous healthy self in which unity and continuity of self is desirable and 'moves [independently] across a variety of positions and [contexts]' (Hermens et al, 1992 p.189). In contrast to this notion of the autonomous identity the dialogical self is conceived as a multiplicity of 'I' positions in terms of both internal and external dialogues;

The I fluctuates among different and even opposed positions and has the capacity to imaginatively endow each position with a voice, so that dialogical relations between positions can develop. These voices behave like interacting voices in a story, involved in a process of question and answer, agreement and disagreement. Each of them has a story to tell about its own experiences from its own perspective. (Hermans, 2008)

The dialogical self is therefore multi-voiced and although there is differentiation in these internal and external voices, 'unity' can be achieved in the relationship between the voices. The dialogical and narrative voices are more open to influence, negotiation and therefore innovation than the autonomous voice. Internal dialogues are 'less organised, more abbreviated and more impulsive than external dialogues' (Wiley, 2006, p.5).

MacIntyre, (1984, p.217) suggests narrative identity entails a 'unity of character, which the unity of narrative requires, without such unity there would not be subjects of whom stories could be told'. MacIntyre argues that the self-narrative is only knowable against the background that culture makes available. Frank (2010, p.53), following Bourdieu, (1977), has created the term 'narrative habitus', part of which involves:

a repertoire of stories that a person at least recognises and that a group shares. These stories are known against an unseen background of all the stories that a person does not know and stories that do not circulate with any particular group.

Dominance and social power in society at large are transferred to the individual self, which consciously and unconsciously absorbs these collective voices which then become available to internal and external dialogues of the individual. An individual speaker's utterance is not simply coming from an isolated, decontextualised voice speaking in a neutral space (Bakhtin, 1986). 'In the process of dialogue, the words that people use are laden with cultural meanings they have accumulated throughout their lives. Individual voices are deeply

penetrated by the culture of institutions, groups, and communities in which they participate, including their power differences.’ (Hermans, 2004, p.297)

Within participant’s accounts there were examples of ambivalence in their internal dialogues, where one voice was more dominating than another voice. In most of the internal dialogues of young people, the opposing voices are saying on the one hand: ‘I cannot influence others because of my condition, and the ways others respond to it’, and on the other hand: ‘I will not let the condition dominate my life and relationships’.

In Lillian’s story, her internal competing dialogue was in favour of the resolve not to let the condition dominate her life. Lillian’s internal dialogue would present itself (as identified by Gonçalves and Ribeiro, 2012) as the contrast between problematic self-narrative and a new ‘innovative moment’ that gave her access to a process which allowed for the transformation from the former to the latter. Lillian’s movement of thought and position was facilitated by a partial acceptance of the loss of previous plans and hopes, and the ability to imagine a different future. However, Lillian was an exception within the young person’s groups, and although there were brief comments by other group members which alluded to I-moments the problem self-narratives largely continued to dominate their accounts.

In the parents’ focus group the parent Louise shared her internal dilemmas within the group, with a profundity that I think influenced other group members to share their own personal dilemmas:

‘I think it [MUPS] does knock your confidence as a parent really because it throws you into two minds all the time, whereas before, when a child’s well, it’s kind of straightforward isn’t it? You have to make decisions and sometimes they are hard decisions, but they are never as hard as when you don’t know what’s the best thing for your child anymore.’ (Louise)

Louise's account includes a number of examples of ambivalence and self-reflexivity, which belies a stereotypical presentation of parents of MUPS sufferers. Her child has been ill for some years and her dilemmas are more about how to go on with life rather than a search for truth about her daughter's condition. From a dialogical perspective, Brinegar et al. (2006) apply the metaphor 'rapid crossfire' to describe the fluctuation between two overt expressions of contradictory internal voices which seem to fight for the possession of the floor.

The doctors' and healthcare professionals' accounts also contained examples of ambivalence, uncertainty and anxiety in their dilemmas about how to manage MUPS patients. However, unlike young people and parents, their internal 'collective voices' were primarily drawn from professional selves rather than more personal stories from 'interpretative and communal traditions'. Most of the doctors and healthcare professionals chose not to respond to the researcher's question about whether personal life experiences had any influence upon their clinical practice with MUPS patients and their families. Thus, internal dialogues would reflect their professional concerns about whether to continue to investigate or not, or the pragmatic dilemmas and risks in managing MUPS patients.

The professional and institutional world of the hospital continues to be predominantly modernist in its language, with values based upon an epistemology that sees 'knowledge' and 'truth' as external to the autonomous identity. In terms of dialogical self-theory 'the power differences between collective voices and in a particular community appear as power differences or power struggles between positions in the internal self. (Hermans, 2004, p.192)

Social constructionist theory suggests that it is not easy for doctors and healthcare professionals to access the relational and multiple truths of dialogical and narrative world-views because the language they have inherited from the past is so deeply embedded in individualism. 'We have 2000 terms in the English language that refer to ('make real') individual mental states' (Gergen,

2000, p.8). The sociologist Callero (2003) also notes a number of concepts that are utilised in mainstream psychology that define the self as 'bounded'.

In terms of my own approach, there are dangers in seeing the dialogical and narrative theories of self in direct opposition to the autonomous self, as the latter continues to dominate the culture and practices within society's institutions. I would suggest that researchers see the differences as complimentary ways of seeing experiences within their research practice. I would concur with Mattingly's view (2010, p.47) that dialogical and narrative researchers should work to amend large-scale social categories [such as biomedicine] and see them as 'cultural resources that inform life on the ground not as containers that enclose it'. Finally, although the concepts behind the theories of the dialogical and narrative self have developed over recent years, further empirical studies are required to either replicate and/or expand upon the themes identified in this research study in MUPS.

For the rest of this Discussion Chapter I will continue to expand on theoretical frameworks and the themes arising from the Dialogical Narrative and Thematic analysis.

6.2 The Story of MUPS – an Absence of Emplotment and Finalisability

In diagnosed illnesses it is possible as Good et al. (his challenges 1994) observe to change a patient's time horizons by establishing a link between the course of the illness and medical interventions, thereby establishing a time horizon for illness with the hope of a cure, and a return to former health. This challenges MUPS sufferer's perceptions are that there are no such biomedical context markers to give hope of future horizons. In addition to the lack of legitimisation of their experience by a medical authority, young people with MUPS may contrast their languishing situation with their contemporaries who continue to proceed through their school towards university or jobs, actively engaging in social and leisure activities, perhaps leaving home and living independently.

Such life trajectories punctuate emplotment, albeit with less demarcation of rituals than in traditional societies.

Mattingly (1998, p.46) refers to emplotment as 'what everybody does every moment; make sense of the ongoing flow of life by endowing what happens with direction, boundaries, and general rules about what leads to what else'. Mattingly describes the antithesis of emplotment as to be when 'lived experience' is driven solely by brute experience (1998, p.46). Some of the young people's stories about living with MUPS were suggestive of experiences 'without meaning' with such metaphors as 'numbness' or 'nothingness'.

In Frank's (1995) terminology the young persons' and parental experiences resemble a 'chaos narrative.' Chaos narratives are pre-narrative story attempts that exist prior to the possibility of narrative coherence or anti-narratives (utterances that are in opposition to standard conventions such as chronology or plot' (Jones et al., 2012, p.103). In chaos narratives such as those experienced by young people and parents in this study troubles can be overwhelming leading to alienation or isolation. The above narrative themes of brute experience, chaos and anti-narratives can be identified within the analysis of adolescent and parental accounts. These stories establish a blueprint with the appearance of symptoms, but it is the young people's and parents' initial medical encounter which can lay the foundation of a chaos narrative; prompted by the absence of a medical/cultural legitimacy for their experience.

6.3 Deconstructing the Processes in Healthcare Professionals' Medical encounters with MUPS Sufferers and Their Parents

'When we demand certainty, patients oblige with fictive information that conforms to our logico-scientific criteria, but distorts the patients' reality. When we allow ambiguity and mystery their place in the treatment room, patients have permission to offer those narratives as well' (Shapiro, 1993).

If we contrast the stories of the different medical encounters by healthcare staff, young person and parent i.e. in the views quoted at the head of this Chapter, the incongruence between the experiences in the G.P. and hospital consultation becomes apparent. In terms of the doctor and nurse accounts, their knowledge of MUPS is drawn from expertise in disease, and the experience of other patients. This experience leads the paediatric doctor and nurse to speculate about the patient's persistence in searching for a diagnosis i.e. the patient has explored the internet and discovered an 'heroic' cure, or the young person and parent are not ready to hear or be persuaded by the knowledge and experience of the clinician about a way forward. The 'expert status' carries with it the license to utilise pre-understandings in medical and healthcare professionals' formulations. A limitation of applying this kind of knowledge and experience, based on an expert position, is that it is less likely that the professionals will reflect upon their own personal professional stories, which might negatively impact upon the content and processes of the interview.

The mother and son may have spent time either privately or conjointly rehearsing their explanations of symptoms to fulfil their pre-conceived notions of what is expected of a patient in a diagnostic interview. In the extracts they report they did not feel listened to or believed by the doctor. Matthew considered that the doctor implied that he had superior knowledge of his own experience than he himself did. Mother and son's recall of the encounter was they were given negative attributions by the doctor such as 'liar' or 'fussy parent'. Labels, when given by those invested with social authority, can stick and finalise subjects and continue to reverberate via comments in the medical notes which can also set a tone for future medical encounters.

Howard Brody, (2004, p.3) formulates the medical encounter as follows:

To deal with the part of medicine which treats everybody as the same, we must extract the narrative from the patient and recast it as a case history or as a medicalised telling of the story...If we do only this, we dehumanise the patient, fail to address him or her as an individual and ultimately may very well increase the patient's suffering.

The initial and subsequent medical encounters are extremely significant for MUPS sufferers and their families. The adolescent may or may not be given a label for his/her bodily experiences, but alternative medical/psychiatric and other explanations drawn from the healthcare professional's 'clinical experience' can produce labels and stories that can be pathologising (White and Epston, 1990). Rudi Dallos (2004, p.41) points out that a strength of a narrative approach is that it sees stories as not just internal to families but

drawn from a pool of culturally shared beliefs...in Western societies there may be seen to be a dominant narrative that distressed states or experiences are a result of inherent personality flaws, organic deficits or biologically inherited tendencies.

There are many epithets that can be attached to young people and their families who live with MUPS – both implicit and explicit. Labels can be very powerful and fixing of subjects i.e. he is psychosomatic or her family is alexithymic, but other terms that historically had their roots in medical annals but without any scientific evidence have entered common usage such as malingerer: 'someone who exaggerates or invents physical or mental symptoms in order to avoid work, school or military service' (LeBourgeois, 2007). The label implies a deficit in one's character and fits well in a culture dominated by functionalist morality (Talcott Parsons, 1951) which purports to treat or reform characters with such traits to make them functional productive citizens again.

Alexithymia is becoming a more fashionable condition in psychiatric and medical domains and refers to individuals or families with 'difficulties in describing and identifying feelings, a limited capacity for imagination, fantasy and externally-oriented thinking rather than reflection on inner experience. (Sifneos, 1975)

Through the discourse of 'objective' biomedical science, professionals as 'scientists learn to impose an artificial, impersonal order on the world and to equate that with reality' (Hurwitz et al., 2004, p.3). I have wondered whether the

medical context can be likened to an alexithymic culture; a term which historically has been attached to patients and their families, whereby 'emotion talk' or shows of feelings are overtly and covertly discouraged in an attempt to sustain a routinised medical clinical environment designed to portray an image of order, knowledge and control.

However, most medical encounters under such conditions may run smoothly up to a point, with a certain amount of mimesis on the part of the actors until the stories begin to diverge. The stories from this analysis usually led to conflict when young adolescents and their parent's failed to get their stories of suffering and symptoms fully heard and afforded social recognition (diagnosis) by a doctor empowered to sanction the disease. Issues of little time and a lack of positive emotional postures or hospitality towards the patients' stories of experience, also noted by Fredman (2010), were themes identified from the analysis in this study.

The reaction to doctors' pre-understandings—can invite reactive thoughts and feelings by young people and parents (pre-and anti-narratives) which make it less likely that they will be able reflect upon their part in the process. Defensive emotional postures and rigid positioning in both parties can be carried forward into future medical encounters. However, doctors may feel intimidated by the strength of feeling of parents who persist in seeking a concrete label for their adolescent's distressing illness experience, which the doctor, having run multiple tests, has no scientific evidence to bestow.

Launer, a G.P. trainer (2002) suggests that health professionals come to consultations with a rich set of prepared narratives in mind, including the rules of their professional practice, professional knowledge, training, personal and professional beliefs. In addition, they may see their role is to 'make people better' on the basis of good evidence-based medicine and persist at pursuing a diagnosis at times on the basis of exclusion – informed by thoughts of complaints or litigation, or stories from colleagues when serious aetiology has been discovered following an initial 'unexplained' assessment.

One can account for this incongruence within the medical encounter beyond the 'factual accounts' using different theoretical frameworks such as frames and knowledge schemas between patients and professionals as identified in the Literature Review: Tannen and Wallerstein (1999) Kleinman (1980); Mishler (1984). Alternatively, one could refer to systemic psychotherapy which has incorporated a model of abstracting meaning in conversation in the theory of coordinated management of meanings, CMM, (Cronin, Pearce and Tamm, 1985).

CMM is a sophisticated multilayered tool for coordinating and managing meaning in social interactions and could productively be applied to dialogical narrative research in medical encounters between doctors and patients. The CMM framework offers a method for the deconstruction of the anomalies of meaning in social interactions, like the medical encounter, when for example a speech act or proposition by a doctor is perceived as having little value or meaning when received through the lens of the cultural context of the patient.

In the initial assessment medical encounters, doctors implicitly and explicitly seek to preserve the canons of the restitutive medical model. In secondary care medical encounters, paediatricians and the nurse specialists may supplant the medical diagnostic discourse for an evaluative non-medical clinical formulation based on their knowledge and experience of other young people and families with MUPS.

As Mattingly (1998) has observed, professionals are likely to tell stories when they need to make sense of difficult relationships with subjects whose behaviour directly affected their own work, including patients and managers. In common with Mattingly's (1998) analysis of occupational therapists' accounts of work with their young patients, the nurse specialists and paediatricians working with adolescents with MUPS also appear to require 'a recounting of past events in order to situate their current work' (p.6) In both initial and subsequent consultations, the doctors and healthcare professionals construct non-medical explanations based upon 'past experience'. Such stories could be viewed as sub-plots to the main medical restitutive narrative.

Non-medical interpretations based upon previous experience can define the boundary and authority of the diagnostic discourse. Knowledge based upon past experiences, as part of a professional or personal narrative, can also dominate the consultation as much as 'truth stories' about symptoms and diagnosis. Meanwhile, young people's and parental perceptions are that their testimonies have not been fully heard or registered by the doctor or team, and non medical judgments based upon experience of healthcare staff may be received as patronising. Alternatively, the content and process of the medical encounter can leave the young person and their parents with feelings of hermeneutic injustice within the restricted social norms of a medical consultation (Carel, 2012).

6.4 What Can Systemic Psychotherapy Concepts Bring to the Medical Encounter to Improve Communication?

Consideration of the medical consultation as a restricted social norm is important in terms of the how much tolerance is afforded to emotional, familial, and cultural stories of doctors and their patients, which are beyond the parameters of what is considered to be relevant biomedical 'facts' for a thorough assessment of symptoms.

Launer (2002) is known for his practical guide for introducing narrative concepts and practices into primary care, although I believe these concepts work equally well if developed as a framework by specialist hospital health professionals who work with MUPS in both contexts. Launer (p.26) introduces three fundamental concepts that healthcare practitioners need to re-orientate towards:

- 'The narrative approach involves seeing the world in terms of circular, rather than linear, processes
- The medical encounter should be a co-created conversation
- Central to the encounter would be the art of curiosity by the healthcare professional'.

Barratt (2005) has had a long experience of collaborative practice with a G.P. colleague, Dr. Jack Czauderna in primary care consultations. Barratt (2005) has highlighted some important advantages of collaborative practice between medical practitioners and psychotherapy. She introduced principles of the reflecting team (Anderson, 1987, p.81) into consultations with individual adult patients. In collaborative practice both G.P. and psychotherapist need to consider the physical:

When a patient consults a doctor about a physical symptom, the notion that the prescription may be for psychotherapy rather than chemical intervention may be difficult to hear especially in a ten-minute consultation. Listening with a therapist present may open people's ears to listening in different ways.

In collaborative practice the therapeutic and biomedical principles can mutually influence the content and processes within the consultation. Adopting reflective positions can increase the discursive significance of notions of doubt and uncertainty: respect for patients' efforts to share and manage their experiences; open emotional postures, giving emphasis to good intentions and reflexivity towards personal and professional pre-understandings; and attention and care to avoid fixating or finalising language whilst incorporating the aspects of a biomedical assessment. The psychotherapist can also be alert to emotion and cultural stories associated with idioms of distress which may be embodied.

In hospital paediatric liaison services this kind of collaborative joint clinic between paediatricians and family psychotherapists can reduce stigma that may be attached to psychological, mental and emotional health. Dr. Kasia Kozłowska, Child Psychiatrist heads a Liaison service at the Children's Hospital at Westmead, NSW, Australia. Her team offers a rare but important example of MDT work specifically focussed on MUPS. She has had a long-term interest in MUPS and the development of multi-modal interventions. Working at a tertiary level of care, the team describe a mind-body-family-based, multi-modal rehabilitation programme for young people physically impaired by MUPS. In close collaboration with the family an MDT identifies a range of interconnected

problems and target interventions to improve the quality of the young person's and the family's experience as a whole. The team, based in a paediatric hospital, involves multiple modalities including physical therapy, pharmacotherapy, individual and family therapy and an education component – all delivered concurrently. The team have a common ethos, which transcends professional boundaries.

6.5 Exploring Emotional Postures and Modes of Interpretation in Research and Clinical Domains – Developing a Training Model

Dallos (2004), writing about his experiences in a clinical context of anorexia, shares doubts about the engagement process with families who live with young people with the disease; a condition which has features in common with MUPS sufferers, in that the idioms of distress are embodied. Dallos writes that despite his commitment and passion for social constructionist and narrative approaches, utilising these concepts in the domain of anorexia is 'not so straightforward' (p.41). Dallos turned to aspects of attachment theory as an explanatory model for the difficulties he was having in engaging with families with anorexia.

Dallos highlights research on the development of narratives in children and evidence from attachment theory (Macabe and Peterson, 1991; Baerger and McAdams, 1999; Habermas and Bluck, 2000) which resonated for me in terms of the fieldwork and analysis of MUPS sufferers' stories. He refers to 'the ability to develop stories about one's life is a sophisticated skill which is shaped by the ways in which parents talk to children such that the ability can be facilitated or retarded...the emotional context of the family is an important ingredient in shaping the nature of conversations that occur' (Dallos, 2004, p.42) Pursuing a theoretical link between attachment narratives and families who live with MUPS in my view would be a useful comparative research study. However, I turned to another influential writer from the systemic family psychotherapy who has been considering emotional processes and language in Glenda Fredman's work,

believing that she has also given us metaphors which can be seen as lanterns 'that light up an area of dark forest' (Dreyfus and Wakefield, 1988).

Fredman's (2009) ideas on creating a resource-full community resonated with me in terms of what she has to say about emotional preparation and postures for engaging patients/clients in the context of complex professional networks. I think these concepts would be valid if introduced into the training of healthcare professionals to broaden their world-view and increase self-reflexivity over personal professional positions in the medical encounter. They may be equally relevant for qualitative researchers considering staging focus groups as a method of research.

Fredman emphasises that in all social interactions 'we meet in postures that involve our body's readiness to respond and that bodily/emotional postures impact upon the quality of conversation we can have with each other' (workshop slides, p.3). Fredman adapts a term originally coined by Griffith and Griffith (1994) 'emotional postures' to describe how both emotional bodily postures can focus our attention – both for animals and humans. Using the illustration of a herd of deer she talks about postures of tranquillity wherein humans like animals will be focussed on the act of 'being in the moment', reflecting, understanding, taking in, absorbing information, affirming, trusting, musing. She contrasts this position with a posture of mobilisation when the body is alerted to a potential attack, it can become rigid in attack/defence mode, protective, justifying, closing down, and sensitive to criticism. Descriptions given by young people, parents and healthcare professionals within their interactions in the medical encounter were suggestive that when characters are in conflict over truth stories in formal contexts such as doctors' consulting rooms, they may assume postures of mobility.

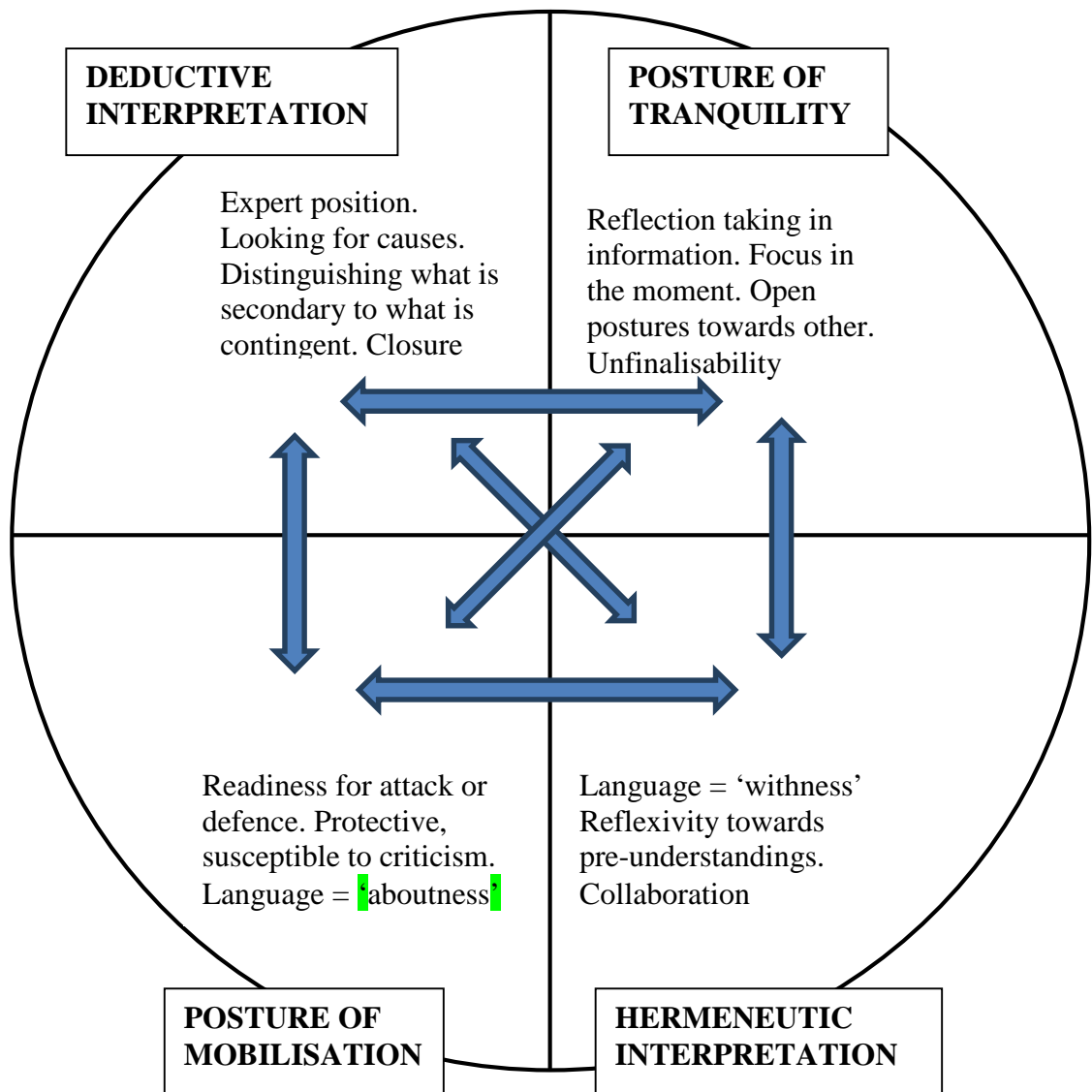
The practice of applying a dialogical narrative analytical (DNA) approach to interpretation, (Frank, 2010) requires the ability to manoeuvre between two different analytical positions: decoding and hermeneutics. Decoding is 'the capacity to sort out what makes a difference from what is secondary or contingent, to trace the cause of what matters and to name the cause' (Frank,

2010, p.93). The decoding method of interpretation in both the material and social science domain has had undeniable successes. However, the nature of the discovery of 'truth' privileges the interpreter's view without much attention to their bias or pre-understandings.

In contrast, hermeneutic interpretation involves an awareness of pre-understandings of the researcher in terms of what is already 'known and believed and requires' the practical necessity of not being 'equally open' to all interpretative possibilities, and the countervailing need to be sufficiently open, lest some valid interpretation be foreclosed' (Frank, 2010, p.94) Thus hermeneutic interpretation 'requires and observes the shifting of horizons, based on an ethical will to understand that which is not immediately accessible to the self but matters crucially to the other (p. 95).

The quadrant (Figure 3) below is an attempt to show the possibilities for different cognitive positions and emotional postures to expand thinking about discursive and emotional postures within the social interaction of a medical encounter. The model is aimed primarily at training for healthcare professionals and psychotherapists who may be involved at various points along the care pathway for young people and parents who live with MUPS. It would constitute an analytical tool for training rather than a map for therapeutic change. It recognises the existence of both monologue and dialogue, deductive and hermeneutic, and that tranquil and mobile postures can exist in the same interactional encounter. However, the introduction of a hermeneutic stance by the healthcare professional incorporating a posture of tranquillity, greatly increases the potential for a more collaborative and richer dialogue with MUPS patients and their parents. The encounter however, continues to have access to the physicians' biomedical deductive knowledge, which is necessary to facilitate movement and negotiation between different positions and emotional postures during the course of the interview.

FIGURE 3: THE POTENTIAL FOR DIFFERENT COGNITIVE POSITIONS AND EMOTIONAL POSTURES IN THE MEDICAL ENCOUNTER



Following the completion of the thesis I aim to select and prepare aspects of the learning from the research. I would like to publish a paper, along the lines of *'The Story of the Medical Encounter – the Space Between the Physician and Young People and Their Parents who Live with MUPS'*. I would include the model in the paper which I hope would be read by healthcare professionals and their trainers. I also would be pleased to exchange understanding and feedback from others with a research and clinical interest in MUPS. I believe a central message emanating from my learning which I would wish to circulate within the research and clinical community is that holistic understanding and care for MUPS sufferers demands a cross-disciplinary dialogue, working towards models of truly collaborative practice.

MUPS and Social Isolation – the Impact upon Adolescent Identity

'Only in relationship can you know yourself, not in abstraction and certainly not in isolation.' Jiddu Krishnamurti (1895-1986)

Post modernist and social constructionist authors have been critical of the modernist concept of the self as a stable, autonomous essence of a person (Anderson, 1997; Hoffman, 1991). Family psychotherapists have preferred to view the self as an on-going autobiography. 'The self is an ever-changing expression of narratives, a being and becoming through language and storytelling, as we continually to make sense of our world and others' (Anderson, 1997, p. 216).

The post-modern definition of the adolescent self contrasts sharply with the theory of adolescent psycho-social theory of identity development (Erikson, 1968). Erickson maintained that adolescence is a time when a coherent sense of self must be developed, and he introduced the term 'identity crisis' to describe the largely 'internal' struggle of the adolescent to establish a stable self.

Erikson's model has been criticised for its male gender bias and rather formulaic nature of moral development (Sayers, 1991; Frosh, 1991) suggests the model underestimates the impact of modernity upon adolescent thought and agency. The impact of modernity and post-modernity upon adolescent development has served to blur the boundaries between adolescence and adulthood.

Charlotte Linde's (1993, p.98) seminal work on life stories identifies that narrative is:

amongst the most important social resources for creating and maintaining personal identity. Narrative is a significant resource for creating our internal private self and is all the more a major resource for conveying that self to and negotiating that self with others.

Linde, identifies three aspects of the narrative self which have significance for the subjects in the current study, 'continuity of self (through time); the relation of self to others; and reflexivity of self 'or the treatment of self as other, including moral evaluation of self' (p.38). In a later work, Linde (2009) identifies the importance of memory in affirming identities and how personal identities interact with collective institutional identities.

A case can be made arising from the analysis of the young people's and parental stories that based on the above features MUPS sufferers fail to meet the criteria for the fulfilment of an emergent narrative self. Some young people found it painful to remember the achievements in leisure and academic activities prior to the onset of symptoms, as it reminded them of the loss of capacities. In other stories from MUPS sufferers the discontinuity of time had also become a source of anguish or despair as the illness had interrupted their narrative trajectory or 'a simple order that consists in one being able to say, when that happened, then this happened' (Frank, 2010, p.115). MUPS sufferers also presented stories that severed or isolated themselves from others:

Matthew: 'I'm not sure really 'cos I never really talk to people about things; it's just how I deal with things, I just withdraw and try asking to deal with it myself. I think I find it more comfortable to pretend it's not there when I need to: there are points where not thinking about it is best.'

Lillian: 'I think half of it I dealt with by myself and then obviously my mum knew and some of my friends and because I didn't want to broadcast it really yeah...I went through a phase where I was kind of scared to meet new people because if it happened they might be shocked or upset.'

George: 'Keeping them happy keeps them away from me, shuts them up kind of thing, like I will deal with not feeling fine on my own.'

Thus through the analysis of young peoples' and parental accounts the absence of all the necessary ingredients for narrative coherence in the development of the adolescent self as outlined by Linde (1993, 2009) became apparent. The tendency of the young person towards social isolation also severed his relationship from the stories of other young people in their pursuit of identity and the collective stories of identity necessary for subjects to gain a sense unity about who they are. As Frank remarks 'selfhood always trades in borrowed goods' (Frank, 2012, p. 36).

The stories of focus group members also contained elements of 'inner and outer conversations'. The illness stories of young people involved a 'closing down' or unwillingness to engage in outer conversations about the nature of their problems in favour of inner conversations.

In undertaking the dialogical narrative analysis of stories of young people, parents and healthcare staff one could see idioms of 'self' as presented through a modernist paradigm i.e. the self as a discreet, internal, finalised subject. In constructionist and narrative perspective the 'self' is constructed through the flow of narratives between 'inner and outer conversations' (Rober, 1999). The concept of the inner conversation has been applied in family therapy training and practice in terms of how the self of the therapist interacts with the role of the

therapist in a therapeutic encounter with a client. I found the concept of inner and outer conversation very relevant to connecting to life world experiences as well as therapy.

As a child I lived most of my childhood and adolescence in an isolated home surrounded by beautiful farm and woodland, and even as a small boy the two-mile walk to and from school was an opportunity to ponder over my day's experiences, daydream, or to consider how to make up with a friend I had fallen out with. The adolescents in the focus groups occasionally shared similar experiences of solitary moments, spent trying to process life events:

George and Matthew's inner reports about their outer responses do seem entrenched with some powerful pre-suppositions about how their friends and others would react if they were to engage in 'outer' conversations about their problems. However, the glimpses that we are given of 'inner' conversations and self-narratives involve sadness, despair, anger, 'numbness' or in a 'brain fog' or 'going round in circles'. There were some other examples of inner conversations which indicated alternative, more hopeful 'quest' narratives, 'There are others worse off than me', and thinking which included ambivalent positions, 'I could have hid myself away, or make an effort to get back to doing things again'. These kind of ambivalent narrative trails appeared most frequently in Lillian's story.

Cheryl Mattingly (2010, p.48) has identified the potential for coherent institutional healthcare narratives to shape and oppress patients and she contrasts this with broken, fragmented and inchoate illness narratives of sufferers:

When illness is protracted, when there is no chance of return to the person one once was, or when there is no hope of being 'normal', a person's very sense of self is lived in a special way through the body. Personal identity becomes tied to pain, uncertainty and stigma that come with an afflicted body. What might it mean to be a healed when a cure is only a distant possibility or no possibility at all?

In the above quotation Mattingly is referring to sufferers with chronic illness but her proposition, in my view, is also equally relevant to adolescents and families who live with MUPS. Her assertion that there is 'no chance of return to the person one once was' resonated with me in terms of the adolescent's adjustment to loss of childhood as well the impact of symptoms and illness on identity.

Social and sexual fears associated with body image and emotional uncertainties can lead the adolescent to yearn for the more sheltered period of early, or middle childhood. Furthermore, there were a number of examples in the young people's and parental accounts of family members' illness and attachment narratives which may have shaped intra-familial relationships in relation to loss, anticipatory loss, protection, mutual dependency, attention; examples that highlighted risks involved in separation. Illness and attachment narratives in past and present family dynamics can be a 'bind' upon movement of thought and behaviour in periods of transitions in family life. These 'binds' can also serve to constrain the expression of an adolescent's sense of self and narrow opportunities for future separation of self and other.

The experience of social isolation, reinforced by physical symptoms and the absence of cultural recognition for distress makes it less likely that the young person with MUPS will re-engage with social life and activities. Without this re-engagement it makes it less likely that the young person will develop an identity that is open to external dialogues and stories that can bring meaning to experience and assist the overcoming of negotiating obstacles in the external world in order to continue their journey into adulthood.

6.7 Public Advocacy Private Doubt – The Experience of Living with an Adolescent with MUPS

‘My experience of illness was a series of disconnected shocks and my first instinct was to try and bring it under control by turning it into narrative, always in emergencies we invent narratives.’ (Broyard, 1992, p.19)

Although the above quotation is referring to the author’s response to learning about his terminal illness, the notion of sense-making or reconstructing an inchoate or chaotic experience into a narrative to ‘bring it under control’ strongly resonated with the stories I have been analysing of young people and parents who live with MUPS.

A narrative framework is well suited to moving between the highly particular and the large-scale societal and cultural discourses, in a practice-oriented way ‘because narratives show us life in process’ (Mattingly, 2010, p.4).

However, making sense and trying to reclaim control over chaotic experiences, uncertainties and vulnerabilities that MUPS can bring to a young person and the family can be extra challenging. Parental and MUPS sufferers’ perceptions of their initial encounters with doctors suggest they did not feel their symptoms and distress were recognised. Despite some young people later being in receipt of a diagnosis they continued to feel sceptical and mistrustful of professionals in medical and educational institutions. This breach in relationships and external dialogues with professionals also excludes young people and families from accessing professionals who hold psychotherapeutic paradigms that would recognise and define their distress more broadly.

As young people’s and parental accounts suggest, illness narratives are not easy to tell or construct without medical or social recognition. I can appreciate what is at stake for parents as they strive to preserve the integrity of their child and family by questioning medical expertise of a non-diagnosing doctor, or fighting for their child against a sceptical system, or gaining strength from finding others who are living with similar problems. It was interesting to witness

how at the end of both parent focus groups there was a common agreement that all had benefitted from sharing their experiences from other parents who 'understood' through common experiences.

Parents and families can be as equally isolated and mistrusting of medical and educational contexts as their adolescent child. Each parent appeared to appreciate the solidarity of other parents in the focus groups in sharing and listening to their common experiences and advocate roles for their child. Many parental accounts included representing their adolescent in terms of seeking a justice and corroboration of their child's experiences and symptoms. However, parents often find themselves arguing in the liminal space of the doctor's consultation room or school classroom with 'truth stories' in domains where the agenda is set by biomedical and educational conventions. Truth stories can be monological and finalising; they usually contain 'thin' binary stories that refuse elaboration as Frank (2010, p.90) points out: 'this stripped down, facts only telling remains a style; its adoption is more a rhetorical display than an actual guarantee of truth'.

In these contexts there may be suspicions or doubt about the advocacy role that parents undertake by healthcare professionals. In the Healthcare Professionals Focus Group a nurse specialist commented she found it difficult to distinguish between whom was telling 'the truth' between a parent or child. This example highlights the problems of 'truth stories' associated with MUPS between adolescent, parent and professionals when explanations are sought solely from within the modernist paradigm of 'objective truth'. I imagine many conversations in medical encounters between professionals and MUPS sufferers would benefit from the post-modern lens of 'multiple truths' and an appreciation of a dialogical narrative interpretation of events.

In addition, a hermeneutic view would acknowledge that all subjects' stories are their own, but are open to the polyphony of other past and present voices, drawing of the dialogical philosophy of Mikhail Bakhtin (1985). However, such pre-understandings are always present and I can think of many times in the

fieldwork process when I have been thinking and responding in a deductive manner, even though I have set out to take a hermeneutic position.

In many ways 'truth stories' can be important to doctors and other healthcare professionals as they fit well with the diagnostic models of scientific certainties. They may be equally important to adolescents and parents as the alternative of 'uncertainty', which can be a disorientating experience. A European study examined tolerance for uncertainty in differing medical populations and discovered that women, junior physicians, surgeons, and general physicians have higher intolerance to uncertainty (Bovier & Perneger, 2007). In this study healthcare professionals' stories also mirrored the stories of paediatricians and nurse specialists who struggled with the uncertainty of MUPS and drew upon past experiences of unexplained work and personal life experiences to give meaning to their own view of the problems, this included 'truth seeking' (Bovier & Perneger, 2007).

6.8 MUPS – Nobody's Core Business

There is a danger that MUPS in childhood and adolescence will become nobody's core business given the experiences of community paediatricians who speak of little or no training in MUPS, lack of 'time' and limited access to 'expertise' in CAMHS or psychological services. Paediatric consultants in hospital services identified the growth of medical specialism's based around physical conditions as detrimental to MUPS sufferers who may experience multiple changing symptoms and therefore could be engaged in an escalation of specialist appointments. Child psychiatrists in paediatric liaison who suggest that liaison services are seen as the 'Cinderella services' by CAMHS managers and clinicians who are also witnessing increased specialisms for example eating disorders, neurological assessments, and early intervention psychosis teams.

The term MUPS was introduced as it was thought to be a less stigmatising term. Indeed 'hypochondria' has been withdrawn as a disorder in DSM-5.

However,' MUPS has a somewhat ambiguous profile in the new edition. Somatic disorders are now referred to as 'somatic symptoms' and related disorders. 'The reliability of MUPS is limited, and grounding diagnosis on the absence of an explanation is problematic and reinforces mind/body dualism' (DSM-5). Yet MUPS is closely associated with conversion disorders and pseudocyesis (phantom pregnancy). Diagnosis continues to be made on the basis of positive symptoms 'distressing somatic symptoms plus abnormal thoughts, feelings and behaviours in response to these symptoms' (DSM-5 2014). The above quote describes features of a MUPS sufferers' presentation as 'abnormal' rather as a sign of distress about their predicament.

Despite the government and professional policy documents aiming to raise the profile of MUPS both in research and clinical practice, the stories of healthcare professionals, young people and parents point to large gaps in resources for young people and their families.

The idea that there are specialists in child and adolescent psychiatry who are able to deal with 'challenging young people and their parents' appears to be a misnomer if we consider the view of Dr. T an SPR in child and adolescent psychiatry:

'I think that apart from PLS, the pathway is clearer for psychiatric conditions like schizophrenia than MUPS. In general adult psychiatry most people would be thinking that their core business was bipolar schizophrenia...I think you come across these problems quite regularly in generic CAMHS. I came across them, but I do not think we get training in the assessment of these sort of problems or even giving them a diagnosis.' (Dr. T)

Dr. T is a thoughtful, advanced trainee Child Psychiatrist, with the advantage of having experience of a range of specialisms in psychiatry and medicine. In this sense he was able to give a 'meta' perspective about the neglect of training in MUPS and to unpick a myth that paediatricians appear to hold that CAMHS has a depth of 'expertise' in relation to the treatment of MUPS. Medical education has been criticised for failing to support the development of skills required for

physicians: self-awareness; exploration of feelings in relation to personal professional roles; and their relationships with child and adolescent patients parents (Polliak, 1992).

The above author supports the notion that physicians fail to see the importance of reflection about their own emotions and they also fail to link self-reflexivity to increase effectiveness in developing rapport and treatment of patients. I also wonder if the dominant professional discourses within medicine, which prizes intellectual 'knowing' over other forms of learning, contributes to the delay in integrating reflexivity and person-to-person skills into a doctor's role. The Community Paediatrician, Dr. D presented a very articulate 'objective' rationale for the problems associated in the field of MUPS, but did not include any ideas about the impact of his subjective role or experiences with MUPS sufferers.

Dr. M and Dr. S the two Child and Adolescent Psychiatrists in the focus groups both spoke eloquently about their practice with MUPS sufferers and their families, introducing their practice of a holistic multi-modal approach and utilising theories from both medical and psychotherapeutic concepts. Both these doctors spoke with commitment and passion in the presence of paediatric colleagues on whom their services are inter-dependent, and yet also dependent; in terms of referrals. At times their testaments left me with the impression that as well as making extremely interesting and moral points about their experiences with MUPS sufferers they were also advocating on behalf of the PLS service. For Dr. S and Dr. M their PLS are at risk and are seen as having little visibility in core CAMHS services.

In some respects respect their accounts reflected an isolation and lack of recognition from the CAMHS establishment and peers. This position of uncertainty reveals ambivalent positions between advocacy in the public domain and anxiety and uncertainty in private moments. Their marginalisation may be isomorphic to the experience of parents of MUPS sufferers.

6.9 Exploring the Learning about Engagement in the Focus Group Method

As discussed in the Methodology Chapter, I believe that family psychotherapists who incorporate a social constructionist and narrative theory into their research practice are well placed to utilise the focus group method for facilitating a safe context and a group atmosphere that is conducive to the expression of stories about events, emotions and more intimate thoughts about their marginalised experiences.

The young people with MUPS and parents who attended the groups shared feedback about their experiences following each session. Five of the six young people who attended the two groups stated they had benefitted from the experience and were pleased to discover that others had undergone similar experiences to themselves in their daily lives.

All eight parents over the two groups also acknowledged the group experience as self-affirming. The social interaction and dialogical benefits of involvement in the research groups was less obvious. The healthcare professionals were all very willing participant group members, but were usually under pressure for time, so whilst these groups were well attended, the process of the groups could be disrupted by late arrivals and early leavers.

My experience in the adolescent groups (not helped by different membership in both groups) was that the groups were more researcher-led than I hoped they would be; despite my attempts to encourage discussion and interaction between group members. The adolescent group members said they preferred having the researcher to guide the discussion with a 'spoke and wheel' question/prompt format.

In future studies, introducing activities – such as showing a film of a doctor/adolescent medical consultation (role-play), or audio or film tapes of other young people's experiences, parental and healthcare professionals' discussions – may allow a greater amount of interaction, co-constructed talk and process between group members to emerge. However, with the seven

focus groups in this study, it became apparent that group members wanted to tell their stories 'in their own ways' (Reissman, 2008).

I believe we were able to create an atmosphere of safety and respectful reciprocity amongst all group members, as everyone appeared to listen carefully to each other's stories, apart from brief interruptions denoting approval with the points being made. However, the exchanges between group members often fell short of 'empowering interaction' (Cohn & Lyons, 2003, p.41) which may have produced more information pertaining to 'difference or trouble' within the social interaction.

In this study 'difference and trouble' remained wrapped up within the group members' particular stories, rather than openly expressed as a dissenting voices in the group dynamic. The healthcare professionals group did produce greater diversity of opinion and I sensed, on occasions, a mild rivalry between some group members.

The theoretical possibilities of the potential of focus groups are however not necessarily translated easily into practice. As the lead researcher, despite many years engaging with young people and families in the family therapy clinic, I was very nervous prior to the first focus group with young people. There are many things to get nervous about: would anyone bother to turn up; would the recording equipment work? I speculated whether young people and parents would really be able to engage in joining conversations about their mind /body/culture experiences associated with MUPS in a meaningful way?

Dallos (2004) and Fredman (2010) led me to consider ways in which to centre the 'voices' of group members by proactively and reflexively considering their experiences prior to a focus group convening. Dallos and Fredman's work suggests clinicians and researches consider preparatory work with families/groups that involves anticipation and ways in which to centre emotional postures of family/group members.

In contemplating my own position I began to recognise more clearly moments when I was processing dialogue or stories from a deductive position or a hermeneutic positions (see earlier discussion of truth stories). I imagined that most group members would join the focus group discussion with stories that would be predominantly informed by deductive or evaluative positions of interpretations of events in the medical and life world. I considered that the role of the host researcher and moderator would be to facilitate a hermeneutic ambience to the proceedings. In this way, deductive and hermeneutic processes are able to be mutually influential in facilitating a resourceful focus group community.

I believe a limitation of this study is that the focus group method did not significantly create new meanings between group members in relation to their experiences. Adolescent, parental and healthcare professionals used the time and space to share their accounts of living and working with MUPS. However, some group members spoke for lengthy periods in order to convey a factual account of events. The result of (particularly parental) eagerness to tell their respective stories of and experiences meant that monological talk dominated in the group process and stifled a more spontaneous dialogue between group members, particularly in the initial stages of the groups. Group members bore witness to each other's stories, which offered some confirmation of the various accounts of their experiences that previously they had not encountered in other institutional contexts.

This experience of 'narrative conformity' reflects Irvine's (1999, p.51) study of group meetings with Co-Dependents Anonymous (CoDA) in which emerges a 'narrative story of good co-dependency...where members tell stories with greater or lesser variation to the core narrative'.

It is possible when constituting groups where the participants have been subject to marginalised experiences, that the initial group processes will reflect a joining up and mutual confirmation of stories that cluster around a core narrative or purpose of the group. However, over time group members will become more

cognisant of 'competing claims to time and identity' (Irvine, p.51) and loyalty to the core narrative is diluted.

6.10 Strengths, Limitations and Parameters of the Study

To my knowledge this is a unique exploratory study in gathering first-person accounts of adolescents, their parents and healthcare professionals who live and work with MUPS. An overarching aim has been to apply a constructionist dialogical narrative lens to the experience of MUPS for adolescents, parents and healthcare professionals.

I hope the readers will feel I have tried to maintain what has been a difficult balance by remaining respectful to the work on MUPS by authors from the modernist tradition whilst profiling and illuminating concepts from language, narrative and culture which enlighten, inform and shape the ways in which all the actors try to make sense of the experience of MUPS. The choice of both thematic and dialogical narrative analysis was an attempt to try to ensure that readers from both modernist and post-modern research paradigms may find use in these different interpretations of what I believe are important testimonies and stories constructed about experience in both the public and the private arenas.

With regard to the focus group membership some young people and parents had been seen clinically by colleagues in PLS and paediatric rheumatology. I also had previous clinical relationships with each of the healthcare professionals who attended both groups. I had to be clear with the all the group members about the difference between a clinical and researcher role in the prefacing the research aims in each group. I invited group members' feedback on this. However, having some prior knowledge and a relationship with some focus group members and the failure to have a wider cultural mix within the young people's and parents group I believe has been a limitation of this study.

In conducting the research I have been open about my research position and theoretical orientation. I have shared with the readers my personal/professional values and assumptions through each stage of the research process. Hopefully, the readers will be cognisant of my commitment to narrative, dialogical thought and practice, and the benefit of this research lens upon the subject of MUPS. By discovering MUPS sufferers', parents' and healthcare professionals' first-hand accounts of their experiences I will be able to share what is important to them with a wider audience.

I believe this study has also critiqued the role of healthcare professionals working in clinical settings with MUPS but more significantly the discourses that have prejudices embedded within them, which can position and oppress MUPS sufferers.

I have included credibility checks on my research positions and respective tasks throughout the research, which included inviting a qualified family psychotherapist to join the focus groups. We were able to give each other feedback and included pre and post-group time with participants, to provide an opportunity for feedback about the content and process within the groups. I also shared a copy of the written analysis at regular intervals who kept an eye to the ethical language within the reports.

I will be informing the participants that the study has ended, and will be happy to meet them to clarify any issues they may have about the final report.

6.11 Theory and Practice Proposals for Healthcare Professionals Working with MUPS

I will now explore the potential benefits for doctors and healthcare professionals who work with MUPS of introducing theoretical concepts from family psychotherapy, social constructionist, dialogical and narrative approaches into their training and practice.

The stories of young people, parents and healthcare professionals' experiences of MUPS suggest it is essential to establish trust within the initial medical encounters before more reflective conversations can emerge. Doctors, healthcare professionals and their patients will benefit from hermeneutic 'witness practices' as opposed to 'aboutness practices' (Shotter, 2011; Hoffman, 2007) discussed earlier in this report.

'Aboutness practices' are common place in medical, educational and social institutions and can involve precipitously giving, or not giving a diagnosis, or introducing damaging treatments evidenced from unconnected expert third-person medical/psycho/social reports about the aetiology of the young persons' physical symptoms and the distress of the family.

Professor Alan Bleakley, writing from the theoretical standpoint of the only medical humanities course (2014) based in a medical school in the U.K., suggests the medical traditions of 'tough-minded patriarchy, individualism and heroism' are being transformed towards a 'pacific, tender-minded practice, where patients and their symptoms must be listened to...medicine and healthcare are also democratising – introducing equality and collaborative methods into team work' (2014, p.7-8). For Bleakley, if this transformation is to take place in medicine it requires a shift in the nature of language adopted by doctors and healthcare professionals, a shift in the genre from the epic to the lyrical from 'the lecture to the song; from the individual to collaboration; from martial metaphors (curing) to pastoral metaphors (caring); from intolerance of ambiguity (dragon slaying) to tolerance of ambiguity' (p.9).

Much of the above is in tune with 'witness practices' which involve healthcare professionals engaging patients with 'open bodily emotional postures' (Griffith and Griffith, 1994, p. 45-48) 'without rank' (Hoffman, 2012), in setting a context of 'authentic hospitality towards the other' (Shotter, 2011), and 'deep listening' (Weingarten, 1998), 'to hear the feelings as much as the content' (Hoffman, 2012) and to be able to introduce questions about the implicit and explicit within a young person's, their family's, and healthcare professionals' accounts of their experience of MUPS.

Establishing a pre-verbal bond with patients will require self-reflexivity from the healthcare professionals about their personal and professional pre-understandings (Fredman, 2009) and a review of the primary goals of the medical interview. Joining families in 'witness practice' will necessitate adding the values of hermeneutic philosophy adding understanding human experience to the scientific deductive knowledge accumulated in medical training.

It will necessitate doctors and healthcare professionals moving towards a positions of collaborative practice in which the practitioner is able to hold the broadest of definitions for the causes of pain and symptoms: keeping an open mind; not knowing too quickly if at all; having an appreciation that some of life's suffering may be beyond the biomedicine compass, and that living more comfortably with uncertainty and doubt is an inevitable part of the suffering of human experience (Sedgwick, 2013).

The above 'witness practices' are necessary if professionals are to respond more effectively to young people and their families who live with MUPS. A collaborative dialogue in the context of greater equality in the doctor-patient relationship is more likely to facilitate an open dialogue and to expand the conversation beyond 'thin narratives' of pain and symptoms to access the familial and cultural stories from the young person's and family's life world. Once this kind of engagement has been established it may become possible to begin conversations about appropriate responsibilities for understanding and managing the young person's distress and suffering, which can incorporate the family and professional network.

Professionals need to stay close to MUPS sufferers and their family's accounts of 'lived experiences'. Early access to family psychotherapy/psychological specialists in MUPS by G.P.'s and hospital paediatric teams will improve outcomes for MUPS sufferers, as will opportunities for joint working and consultations. Psychotherapeutic professionals with experience of MUPS may prevent unnecessary tests and treatments, which will have little or no impact upon symptomatology. Young people and their families will benefit from

multidisciplinary health and social care interventions which will reduce the lengthy periods that many young people spend isolated and withdrawn from health and educational institutions, due to the domination of symptoms and ambiguity about the causes of the condition in these institutions.

The transformation in the practice of doctors and healthcare professionals does not require them to abandon totally their medical expertise, but to remain open to the utility of key concepts from the medical and hermeneutic paradigms in engaging with MUPS sufferers and their families.

6.12 Some Unfinalised Thoughts on the Research

In the spirit DNA and the commitment to unfinalisability in which all endings are seen as only provisional, I see these final thoughts as only punctuation in my continuing research and clinical relationship with MUPS. In what has been a long and sometimes challenging journey, when I have felt lost within a mountain of data or tired of the endless transcribing of the videotape recordings, I generally felt I would re-energise due to commitment to the idea that this research project would be beneficial in highlighting the complexities of the experiences and suffering of young people with MUPS and their parents, and of the healthcare professionals who work with them.

The stories that I heard from young people and their parents were, first and foremost about distress; a distress that went beyond mind/body symptoms into a distress about losses: loss of mental and physical capacities; loss of plans, dreams and hopes; loss of friendships and social life; loss of pleasure and activities in family life; loss of independence for both young person and parents; loss of trust in medical and educational institutions, and so forth.

Therefore I am left with no doubt that MUPS is a condition of distress and loss. However, from the doctors' perspective MUPS remains a challenge because it is a condition of doubt and contested illness, which does not fit neatly into the biomedical restitutive model of healthcare. With regard to doctors and allied

healthcare professional who participated in this research, none were negative or disbelieving about MUPS sufferers' distress, (unlike some doctors' studies highlighted in the Literature Review), but many paediatricians saw MUPS as a problem of clinical management: none had specific training in MUPS but were expected to manage what they saw as complex cases. The psychiatrists and healthcare professionals both held broader horizons and had positive therapeutic ideas about 'witness' practice but were frustrated by a rigid adherence to psychiatric diagnostic criteria which often left MUPS sufferers excluded from accessing CAMHS.

With contested conditions or MUPS young people and families are reliant on the ability to find a language to convince doctors about the problem, if you do not have access to this kind of language you may be completely abandoned. In this research young people and parents felt they had been treated badly by doctors who had not only disregarded their stories of symptoms but had attached non-medical labels to their presentation. Not only can doctors and healthcare professionals have the finalising words about patients, they underestimate I believe the impact of those words on the confidence and credibility of the young person and their family. As a consequence young people may choose isolation and withdrawal from social activity and relationships and 'cut themselves off' from the dialogical world. Resorting to inner dialogue alone may also be due to other pre-illness stories or family patterns of communication.

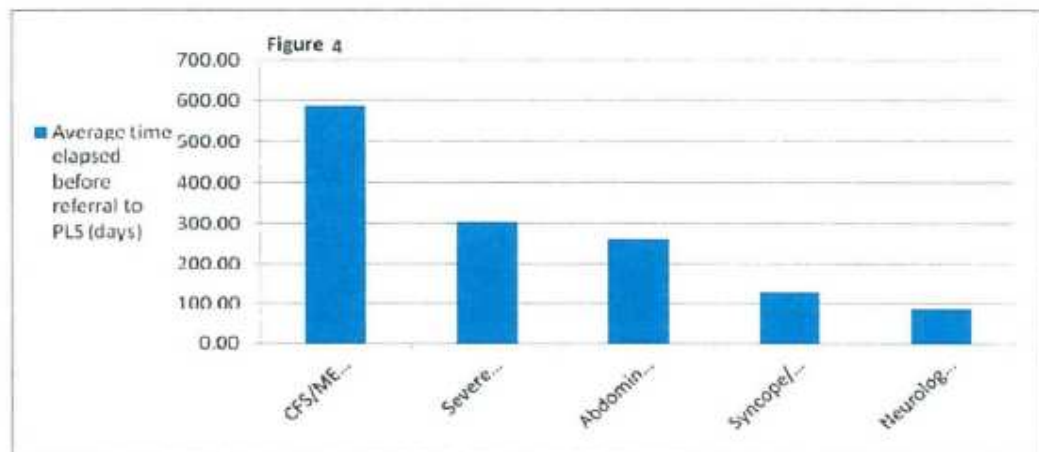
APPENDICES

Appendix 1

unexplained weakness and seizures (average delay 87,5 days).

Table 1

Symptoms	Average time elapsed before referral to PLS (days)
CFS/ME symptoms	587.25
Severe pain	302.75
Abdominal pain/ Nausea/ vomiting/ weight-loss	263.25
Syncopal/dizziness	126.00
Neurological symptoms (weakness, seizures)	87.50

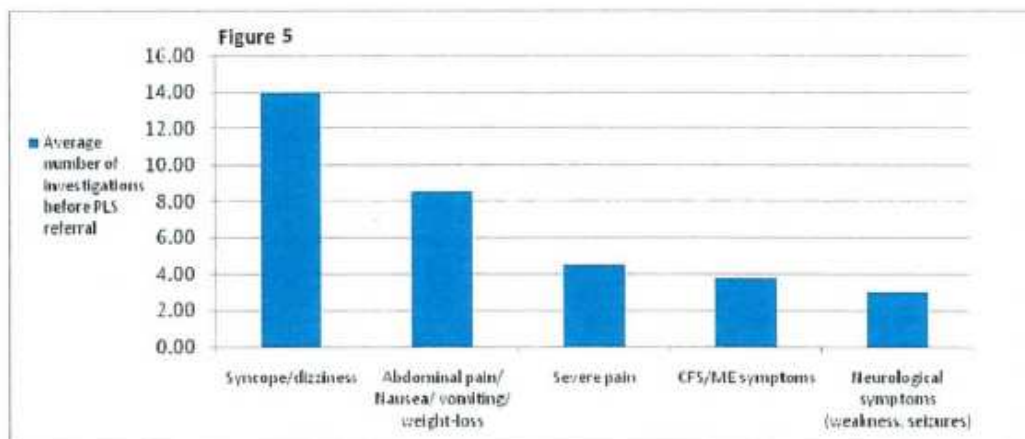


2) Investigations & Invasive procedures

The number of investigations carried out (table 2; figure 5) was greatest for patients with syncope and dizziness, with an average of 14 investigations per patient, and abdominal pain, nausea and vomiting, with an average of 8.5 investigations per patient. Patients receiving the fewest investigations were patients with symptoms of CFS/ME (average 3.75 investigations per patient) and neurological symptoms (average 3 investigations per patient).

Table 2

Symptoms	Average number of investigations before PLS referral
Syncopal/dizziness	14.00
Abdominal pain/ Nausea/ vomiting/ weight-loss	8.50
Severe pain	4.50
CFS/ME symptoms	3.75
Neurological symptoms (weakness, seizures)	3.00

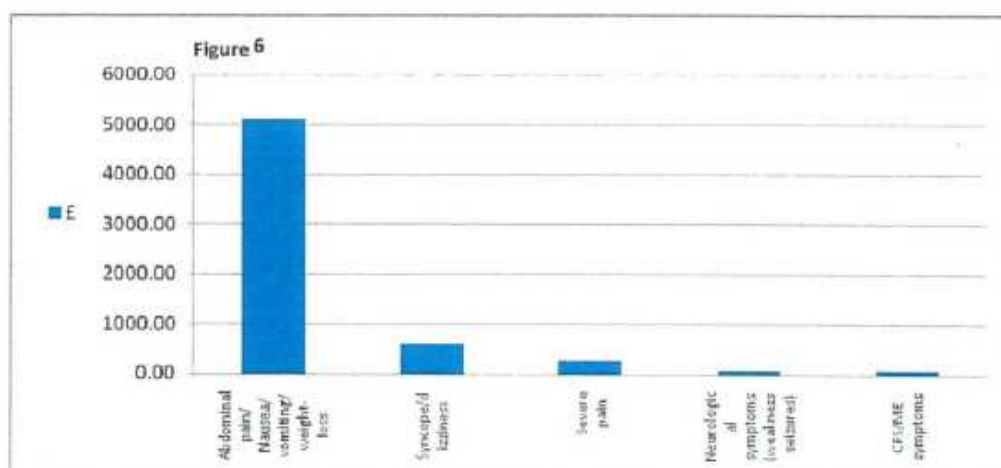


In this sample, the only patients that underwent any invasive procedures were those patients presenting with abdominal pain, nausea and vomiting. These patients each underwent an average of 2.0 invasive. No patients with any other presenting problems in this sample received any invasive procedures.

The combined cost of investigations & invasive procedures (*table 3; figure 6*) was highest for patients presenting with abdominal pain, nausea and vomiting, with an average cost of £5106 per patient. Patients with symptoms of CFS/ME presented the lowest cost for these measures with an average cost of £79 per patient.

Table 3

Symptoms	Average cost of investigations/invasive procedures before PLS referral
Abdominal pain/ Nausea/ vomiting/ weight-loss	£5106.00
Syncope/dizziness	£612.50
Severe pain	£262.75
Neurological symptoms (weakness, seizures)	£95.50
CFS/ME symptoms	£79.00

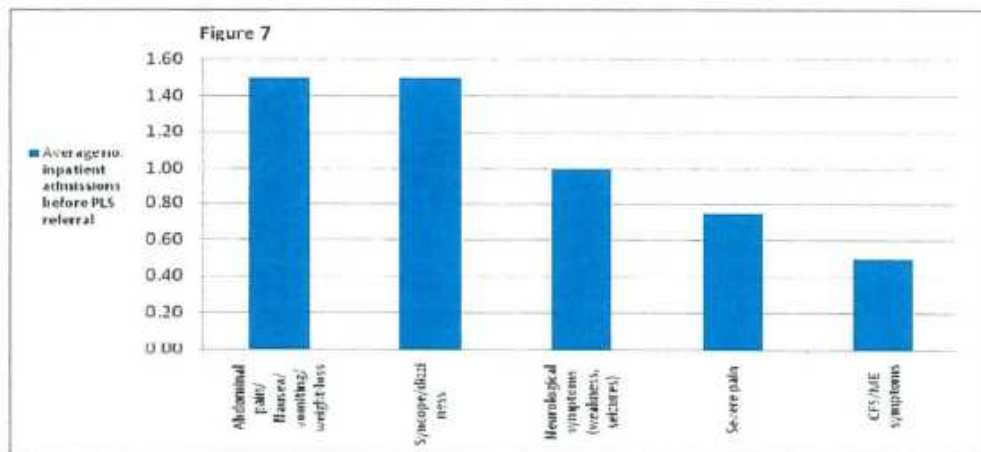


3) Inpatient and A&E Admissions

The number of inpatient admissions was highest amongst patients with abdominal pain, nausea and vomiting, who had an average of 1.5 inpatient admissions per patient. The lowest number of inpatient admissions was for patients presenting with CSF/ME symptoms who had an average of 0.5 inpatient admissions per patient.

Table 4

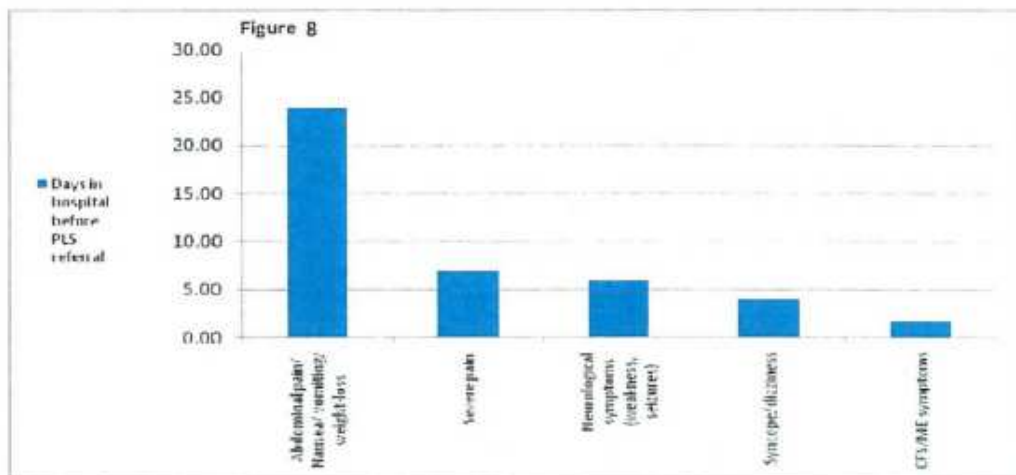
Symptoms	Average number of hospital inpatient admissions before PLS referral
Abdominal pain/ Nausea/ vomiting/ weight-loss	1.50
Syncope/dizziness	1.50
Neurological symptoms (weakness, seizures)	1.00
Severe pain	0.75
CSF/ME symptoms	0.50



The number of days children were admitted as inpatients (table 5; figure 8) was again greatest for patients with abdominal pain, nausea and vomiting who spent an average of 24 days in hospital, and was lowest for patients with symptoms of CSF/ME with an average of only 1.75 days.

Table 5

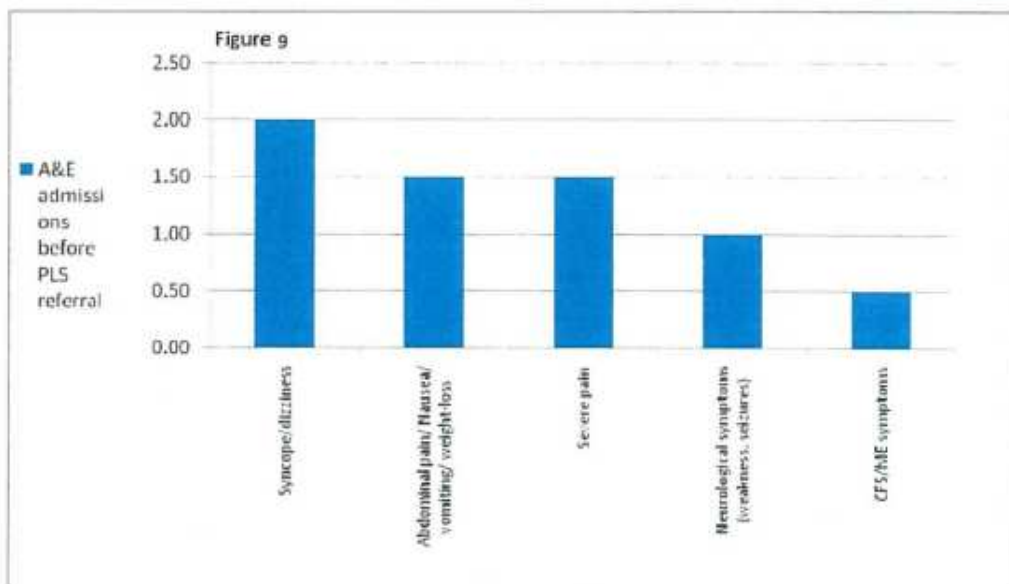
Symptoms	Average number of days in hospital before PLS referral
Abdominal pain/ Nausea/ vomiting/ weight-loss	24.00
Severe pain	7.00
Neurological symptoms (weakness, seizures)	6.00
Syncope/dizziness	4.00
CSF/ME symptoms	1.75



The number of A&E admissions (*table 6; figure 9*) was greatest for patients with syncope and dizziness, with an average of 2 A&E admissions per patient, and lowest again for patients with symptoms of CFS/ME with an average of 0.5 A&E admissions per patient.

Table 6

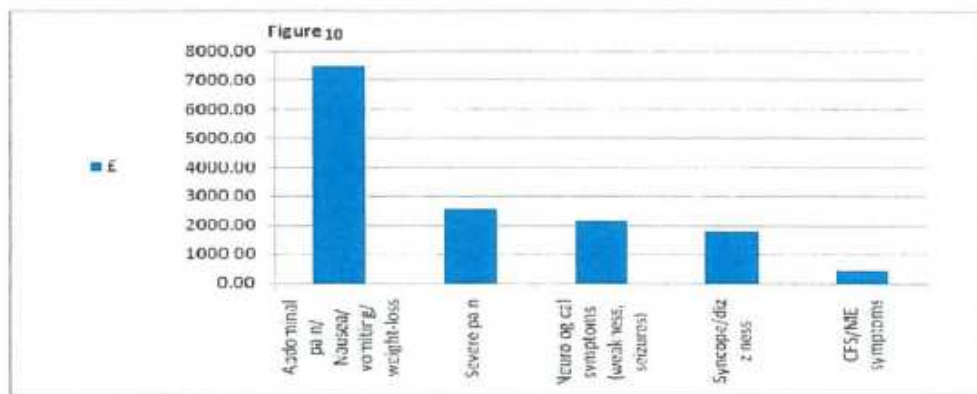
Symptoms	Average number of A&E admissions before PLS referral
Syncope/dizziness	2.00
Abdominal pain/ Nausea/ vomiting/ weight-loss	1.50
Severe pain	1.50
Neurological symptoms (weakness, seizures)	1.00
CFS/ME symptoms	0.50



The combined cost of inpatient and A&E admissions (*table 7; figure 10*) was highest for patients with abdominal pain, nausea and vomiting, costing an average of £7492.59 per patient. The combined cost of admissions was lowest for patients with CFS/ME symptoms, averaging £456.25 per patient.

Table 7

Symptoms	Average cost of admissions/A&E before PLS referral
Abdominal pain/ Nausea/ vomiting/ weight-loss	£7492.50
Severe pain	£2573.75
Neurological symptoms (weakness, seizures)	£2175
Syncope/dizziness	£1790
CFS/ME symptoms	£456.25

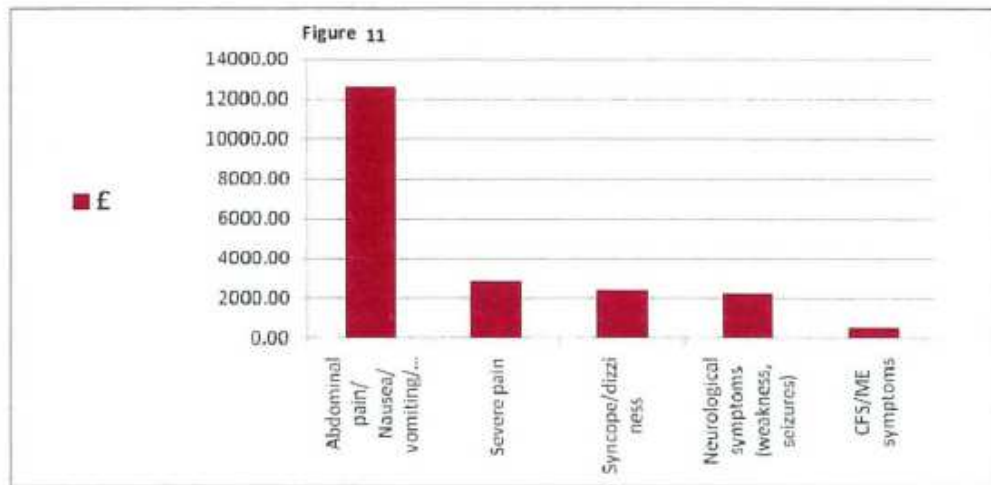


4) Average Overall Cost of Investigations, Invasive procedures and Inpatient/A&E Admissions (*table 8; figure 11*)

Most expensive were patients with abdominal pain, nausea and vomiting with an average overall cost for investigations, procedures and admissions of £12,599 per patient. Least expensive were patients with CFS/ME symptoms with an average of £541.50 per patient.

Table 8

Symptoms	Average total cost of investigations, procedures, admissions & A&E before PLS referral
Abdominal pain/ Nausea/ vomiting/ weight-loss	£12598.50
Severe pain	£2836.50
Syncope/dizziness	£2402.50
Neurological symptoms (weakness, seizures)	£2270.50
CFS/ME symptoms	£541.50

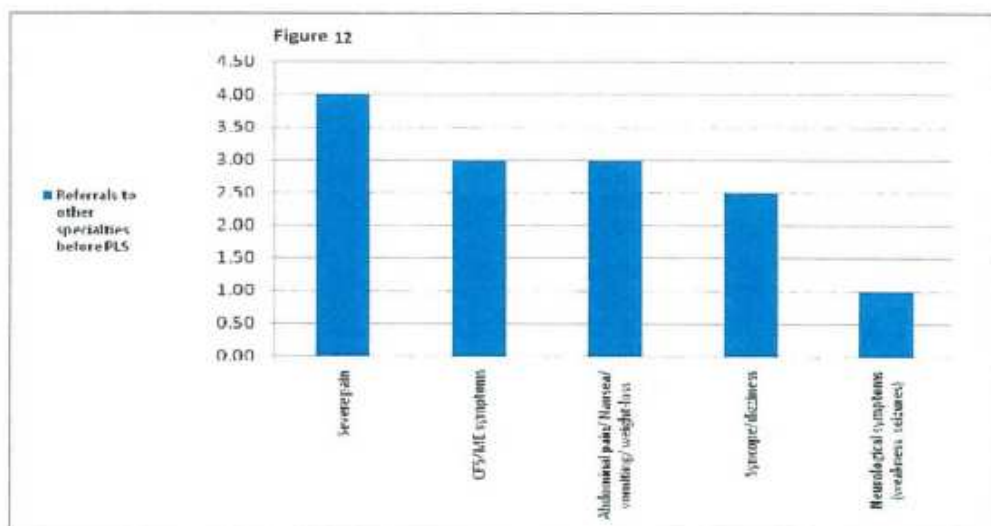


5) Referrals to Other Specialties (*table 9; figure 12*)

Patients with severe pain were referred to the most other specialties, with an average of 4 specialties referred to per patient. Patients with the least referrals to other specialties were patients with neurological symptoms with an average of 1 specialty per patient.

Table 9

Symptoms	Average number of referrals to other specialties before PLS
Severe pain	4.00
CFS/ME symptoms	3.00
Abdominal pain/ Nausea/ vomiting/ weight-loss	3.00
Syncope/dizziness	2.50
Neurological symptoms (weakness, seizures)	1.00

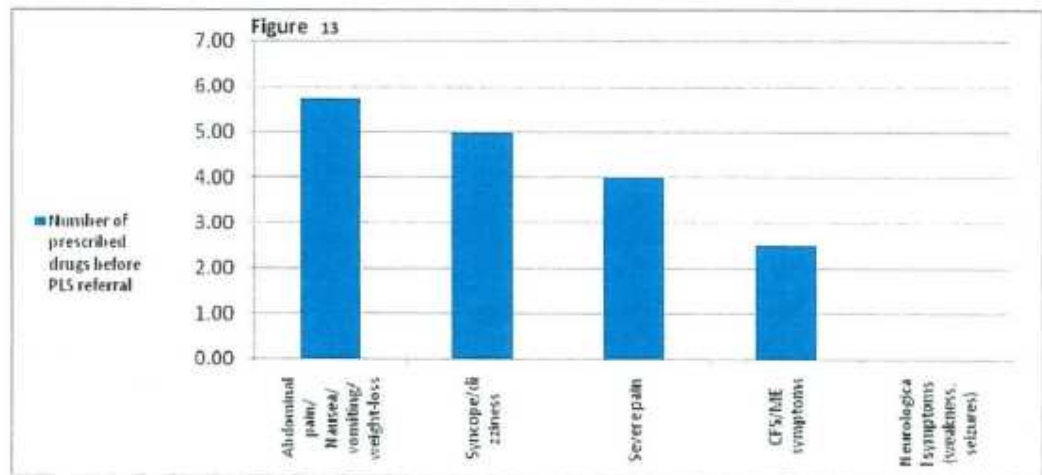


6) Number of Prescribed Drugs (table 10; figure 13)

Patients with abdominal pain, nausea and vomiting (average 5.75 drugs per patient) and syncope and dizziness (average 5.00 drugs per patient) were prescribed the most drugs before referral to PLS. Patients with the least drugs prescribed before referral to PLS were patients with neurological symptoms who, in this sample, did not receive any prescribed drugs prior to PLS referral.

Table 10

Symptoms	Average number of prescribed drugs before PLS referral
Abdominal pain/ Nausea/ vomiting/ weight-loss	5.75
Syncope/dizziness	5.00
Severe pain	4.00
CFS/ME symptoms	2.50
Neurological symptoms (weakness, seizures)	0.00



APPENDIX 2

Neuropsychiatry

Up to the 18th and early 19th Century psychological factors such as the loss of a fortune, the death of a loved one, or disappointment in love were quite naturally accepted by physicians as an important part in the causation of disease.

In the second half of the 19th Century the growing knowledge of pathology and new methods in microscopy led the German pathologist, Virchow, to assume that all diseases were organic, that unless demonstrable cell changes could be discovered under the microscope no disease could be said to exist. Neuropsychiatric approach views the somatomo symptoms much as a disease, much as one would regard pneumonia or cancer. Patients were often diagnosed with hysteria in the absence of a demonstrable physical cause, and yet medics attempted to apply the same pathological approach to mental illnesses.

In the 1980's some biological psychiatrists speculated (Flors-Henry,1983) that information transfer between two cerebral hemispheres across the corpus callosum may be impaired in patients with bodily symptoms associated with alexithymia, in which patients purportedly do not possess language for describing inner emotional experiences (Hoppe and Bogan, 1977).

The Psychoanalytic Approach

In his early work Sigmund Freud saw libido or *the life energy* as a primary shaping force in human behaviour. If through psychic repression libido could not be appropriately expressed through language or feelings then the dammed up libido would express itself through excessive stimulation of a body organ. Selection of the body organ would be determined by the symbolic meaning that had prompted the repression.

Sperling (1977) writing from a psychoanalytic perspective in the 1970's describes most psychosomatic disorders frequently occurring in adolescence. He classifies these disorders in accordance with organ systems: gastrointestinal systems; including the mouth, the intestines, and the anus. Despite the prominence of psychoanalysis for psychosomatic conditions in the early part of the 20th Century it had limited influence on such conditions, probably due to the approach had little success for most cases and has on some occasions exacerbated the conditions (Kellner, 1975; Sifneos, 1975).

In the last two decades the concept of alexithymia has stimulated researchers from the psychodynamic tradition to revisit psychosomatic illness. The analysis Joyce McDougall (1989) links alexithymia to the concept of pseudo-normality, whereby patients may present with superficially adjusted patterns, together with somatic symptoms and concealed disturbance. She stresses its origin in pre-oedipal developmental difficulties, in particular the failure to internalise a benign, care-taking maternal object, "an inner sense of deadness or numbness is typical and can emerge in the therapists counter-transference" (Erskine & Judd, 1994, p.50).

Griffith and Griffith (1994, p.23) suggest that in common with professionals from the four other scientific approaches the psychoanalyst is an expert and the patient and family testimonies about the problem are side-lined in favour of the expert story espoused by the professional:

The psychoanalyst meets the patient with a studied gaze like a wise elder who learned over the years the hidden secrets of life, listening for moments of readiness when the child may be able to hear the story disclosed, using the language of wishes, fears, unconscious mind and interpretations.

The Cognitive/Behavioural Approach

Cognitive and behavioural psychologists discovered in the 1960's that medical conditions previously considered to operate independently of mental regulation, such as blood pressure or EEG brain waves could in fact show learned changes. Principles from learning theory applied through behavioural medicine and in more recent years the emergence of cognitive/behavioural approaches developed well-defined strategies for eliminating unhealthy or undesirable living habits or behavioural or thought patterns. For the success of this approach patients must be able to host the clinician's perspectives and accept their guidance.

Griffen and Christie (2008, p.533) questioned the effectiveness of CBT and Structural Family Therapy when working with MUPS:

Psychological therapies may also be unhelpful. Approaches which look for underlying family conflict are often resented, while CBT approaches may not fit for the young person who cannot see a link between their thoughts and the external experience of pain or fatigue.

Bio/Psycho/Social Approach

A bio/psycho/social clinician meets the patient with skills outside of their professional training by seeing how health problems extend outside a professional setting into the patient's work, marriage and school. Practitioners may use the language of wholeness, systems, beliefs systems and symptom function. In common with the other paradigms the bio/psycho/social professional "provides an authoritative reference for valid bodies of knowledge and methodologies that distinguish between objective and subjective truth.

Griffith and Griffith's (1994) critique of these four paradigms also recognises their contribution to understanding and treating mind/body problems in training

programmes, and they have expanded the conceptual thought through which we consider mind body problems. Yet all four paradigms are deemed to fall short when it comes to a useable general theory when working therapeutically with somatic problems.

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STAFF MEMBER INFORMATION SHEET

Unexplained medical symptoms in children: exploring parents' and staff perceptions

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part

What is the purpose of the study?

Unexplained medical symptoms are a frequent complaint in childhood and adolescence. Symptoms include headache, abdominal and limb pain, and sometimes lead to school absence, distress and frustration within families. This study is being carried out to explore staff perceptions of caring for young people with such symptoms. Research like this will help us understand the experiences of medical professionals who care for these young people and their families.

Why have I been chosen?

You have been chosen because you are a health professional who has experience of working with young people and their families with unexplained medical symptoms.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will it involve, if I decide to take part in the study?

There are two parts to this study:

- The first part involves completing the attached questionnaire which asks for your views and experiences of caring for children with unexplained medical symptoms. It should take between 5 and 10 minutes to answer the questions.
- The second part will involve some of the participants who completed the questionnaire being asked to take part in a discussion group. For this part, you will be asked to come along to a single discussion group with between 5 and 9 other health professionals to discuss your experiences of caring for children with unexplained medical symptoms and their families. The groups will be arranged at convenient locations and times for the participants. Travel expenses will be paid, and refreshments available.

What are the possible disadvantages of taking part?

There should be no disadvantage to you as a result of taking part in the study. The questionnaire will take just a few minutes to complete and you will find a prepaid envelope attached for its return. Your answers will be anonymous.

If you wish to participate in the second part of the study, we will try to arrange your discussion at a time and location to suit you and you will be reimbursed for travel expenses. Your contribution to the discussion will be treated anonymously, and no one will be able to identify you or what you say in any reports of the study.

What are the possible benefits of taking part?

It is hoped that this study will help us to improve the service offered to children with unexplained medical symptoms and their families in the future, and the training and preparation of the professionals who care for them. If you choose to get involved in the group discussion, you will also have the opportunity to discuss your experiences, thoughts and feelings with others in a non-judgemental environment.

What happens when the research study stops?

After you have completed the questionnaire there will be no further involvement unless you have stated that you wish to be contacted for the second part of the study, the group discussions.

For those choosing to also attend a group discussion, you will be sent a summary of the main discussion points mentioned within your group and asked to return a slip commenting upon its accuracy.

For all participants, you will be offered the chance to receive a summary of the overall results in due course.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms may be available to you. However, if you have any concerns about the study please address them in the first instance to the lead researcher (contact details below), who will take steps to rectify the situation immediately.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the department will have your name and address removed so that you cannot be recognised from it.

What will happen to the results of the research study?

The results of the study will be submitted for publication in a relevant peer-reviewed journal after the study is completed. You will be able to obtain a copy of the article or a summary of the results from the lead researcher. You will not be identified in any publication.

Who is organising and funding the research?

The study is organised and funded by the University of Nottingham.

Who has reviewed the study?

The Nottingham Local Research Ethics Committee has reviewed the study.

Contact for further information

For further information, concerns or complaints about the study please contact:

Paul Fletcher

Systemic Family Psychotherapist

Child and Adolescent Psychiatry

E Floor South Block

Queens Medical Centre

Nottingham NG7 2UH

Tel: 0115 82 30269

Email: paul.fletcher@nottshc.nhs.uk

Thank you for taking the time to read and consider this information.

If you decide to take part, please sign and return the attached consent form along with your completed questionnaire.

You may keep this information sheet and the researcher will send you a copy of your consent form for you to keep.

Paediatric Liaison Team

Queen's Medical Centre



YOUNG PEOPLE'S INFORMATION SHEET

Young people's experience of living with unexplained pain/symptoms

Please will you help us with our research?

We are interested in talking to young people who live with pain/symptoms which have not been given a diagnosis by their Doctors. The following information gives details about the study, although you may have some other questions, which we have highlighted. Please contact Paul or Jacqui if you want more details. A member of the study team will telephone you within the next two weeks to ask you if you would like to take part. If you DO NOT want them to contact you, please complete the form at the bottom of this information sheet and return it in the envelope provided (you don't need to put a stamp on this!)

Mr Paul Fletcher
Jacqui McIntyre

0115 8230269

paul.fletcher@nottshc.nhs.uk
Jacqui.McIntyre@nuh.nhs.uk

Why is the project being done?

Researchers have not asked young people and their families very much about their experience of living with unexplained pain/symptoms. We plan to listen to groups of young people and learn about the experience of living with an illness for which there has been no diagnosis. We are very interested in understanding more about young people's and their family experiences of living with unexplained pain/symptoms as this will help Doctors and other professionals responsible for the care of young people to work more effectively.

What will happen to me if I take part?

If you agree, Paul and Jacqui will meet you and the other young people in the group at a place near where you've received treatment, to talk to all of you about your experiences. We will use a tape recorder to record the

conversations, so we can better remember what was said and who said it. The session will last about an hour and a half. We'll be able to stop any time for a break, and we'll make sure that there's something to eat and drink for you.

Who will be in the project?

We'll be talking to 2 groups of young people, with a maximum of six people in each group aged between 14 and 18.

Do I have to take part?

No. It's your choice. If you say 'yes', you can still drop out at any time. If you don't want to answer some questions, just say 'pass', or shake your head. You do not have to tell us anything unless you want to. Even if your parents/carer wants you to, you can still say no and you won't have to take part. Whether you help us or not, you will still go on having just the same care. If you do decide to take part in the study, you and your mum or dad (or carer) will be asked to sign a consent form. You can still withdraw from the study at any time once you have signed this.

Will there be any problems for me if I take part?

We hope you will enjoy talking to us and sharing your experiences with other young people in the group. A few people get upset when talking about their lives, and if you don't want to talk about something and/or stop that's OK. Someone will be available from the paediatric liaison team to talk to during the group and afterwards if you require support. We can also put you in touch with someone to help you, if you like. If you are unhappy about anything that happens in the project, please tell us. You can also tell your parents or someone close whom you trust to let us know your thoughts.

Who will know if I am in the research and what I have talked about?

Apart from Jacqui and Paul there are two other people in the research team. Paul will from time to time discuss the research with a supervisor at the university where he is studying. Your parents will also know if you are taking part in the project, but we will not tell them or anyone else what you have said. The only time we might have to break this promise is if we think you or someone else might be at risk of being hurt. If so, we will talk to you first about the best thing to do.

We will keep our tapes in a safe lockable place and delete your name from the tape at the end of the project. Your name and details will not be kept on

a computer and any information you give us only be seen by members of the study team and their supervisors.

When we write reports about your views, we will change your name, so no one will know what you said.

Will doing the research help me?

We will write a report about what you and other young people say, also including the views of parents and also medical teams and other professionals responsible for your care. It is important for medical and other professional staff to understand what it's like for young people who have been living with unexplained pain/symptoms. So, by taking part, you can help doctors, medical teams and other professionals to improve the understanding of your experience and the ways they manage your care. We hope you (and your parents or carers) might find the report we write interesting too, and you will have an opportunity to meet with us to discuss the findings towards the end of the research. We aim to circulate the report widely and publish the findings in a medical journal.

Will I know about the findings?

We will invite you to a meeting to share the findings and you will also receive a copy the report.

Further Information

Please read the Focus group guidelines carefully. Paul or Jacqui would be happy to answer any questions you may have about these guidelines or the research generally (telephone 0115 8230269 or email paul.fletcher@nottshc.nhs.co.uk). Any travel expenses you or your family incur will be reimbursed and light refreshments will be provided during the group interviews.

If you decide to take part, please keep this leaflet with the copy of your consent form.

Thank you for reading this leaflet!





PARENT INFORMATION SHEET

Unexplained medical symptoms in children: Exploring parents' and staff perceptions

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part

What is the purpose of the study?

Unexplained medical symptoms are a frequent complaint in childhood and adolescence. Symptoms include headache, abdominal and limb pain, and sometimes lead to school absence, distress and frustration within families. This study is being carried out to explore staff perceptions of caring for children with such symptoms, and to find out what parents think about the service they and their child have received. Research like this will help us understand the current strengths and weaknesses of the current situation, and make improvements to both staff training and patient care.

Why have I been chosen?

You have been chosen because your child has previously been under the care of Dr Slaveska-Hollis for unexplained medical symptoms and because your perception of the service you received will be valuable to the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

What will it involve, if I decide to take part in the study?

If you agree to take part in the study, you will be asked to come along to a single discussion group with between 5 and 9 other parents to discuss your experiences of having your child investigated for unexplained medical symptoms. The groups will

be arranged at convenient locations and times for the participants. Travel expenses will be paid, and refreshments available.

What are the possible disadvantages of taking part?

There should be no disadvantage to you as a result of taking part in the study. We will try to arrange your discussion at a time and location to suit you and you will be reimbursed for travel expenses. Your contribution to the discussion will be treated anonymously, and no one will be able to identify you or what you say in any reports of the study.

What are the possible benefits of taking part?

You will have the opportunity to discuss your experiences, thoughts and feelings with others in a non-judgemental environment. It is hoped that this study will help us to improve the service offered to children with unexplained medical symptoms and their families in the future.

What happens when the research study stops?

After you have taken part in the group discussion, you will be sent a summary of the main discussion points mentioned within your group and asked to return a slip commenting upon its accuracy. There will be no further involvement after this, unless you would like to receive a summary of the overall results in due course.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms may be available to you. However, if you have any concerns about the study please address them in the first instance to the lead researcher (contact details below), who will take steps to rectify the situation immediately.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the department will have your name and address removed so that you cannot be recognised from it.

What will happen to the results of the research study?

The results of the study will be submitted for publication in a relevant peer-reviewed journal after the study is completed. You will be able to obtain a copy of the article or a summary of the results from the lead researcher. You will not be identified in any publication.

Who is organising and funding the research?

The study is organised and funded by the University of Nottingham.

Who has reviewed the study?

The Nottingham Local Research Ethics Committee has reviewed the study.

Contact for further information

For further information, concerns or complaints about the study please contact:

Mr Paul Fletcher
Systemic Family Psychotherapist
Child and Adolescent Psychiatry
E Floor, South
Queens Medical Centre
Nottingham NG7 2UH

Email: paul.fletcher@nottshc.nhs.uk

Tel: 0115 82 30269

Thank you for taking the time to read and consider this information.

If you decide to take part, please sign and return the attached consent form. You may keep this information sheet and the researcher will send you a copy of your consent form for you to keep.

Appendix 3

Nottingham Research Ethics Committee 1

1 Standard Court
Park Row
Nottingham
NG1 6GN

Tel: 01159123344 Ext: 39368
Fax: 01159123300

17 January 2008

Mr Paul Fletcher
Department of Child and Adolescent Psychiatry
E Floor, South Block
NUH - QMC Campus
NG7 2UH

Dear Mr Fletcher,

Study title: Unexplained Medical Symptoms in Children: Exploring staff and parent perceptions
REC reference: 04/Q2403/74
Amendment number: 1 - Modified
Amendment date: 06 November 2007

Thank you for submitting the above amendment, which was received on 04 January 2008. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 27 December 2007 refers).

The modified amendment has been considered on behalf of the Committee by the Chair.

Ethical opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Modified Amendment: - Change of CI from P Furness to P Fletcher - Protocol amendments	Amendment number 1	06 November 2007
Covering Letter		04 January 2008
Part B: Section 7 - Declaration		14 November 2007
Protocol (old version)	1	03 June 2004
Protocol (new version)	2	07 November 2007
Participant Information Sheet: Young people	3	04 January 2008
Participant Information Sheet: Staff	2	07 November 2007
Participant Information Sheet: Parent	2	07 November 2007
Participant Consent Form: Young people (16-18 years)	1	04 January 2008

Participant Consent Form: Young people	3	04 January 2008
Participant Consent Form: Staff	2	07 November 2007
Participant Consent Form: Parent	2	07 November 2007

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

04/Q2403/74:	Please quote this number on all correspondence
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Yours sincerely

Ms Trish Wheat
Committee Co-ordinator

Email: trish.wheat@nottspct.nhs.uk

Copy to: *Mr Paul Cartledge, Nottingham University*

R&D office for NHS care organisation at lead site – NUH – QMC Campus

Appendix 4

Doctors Focus Groups Sub Themes

Sub themes	Group 1	Group 2
Two main challenges in working with families with MUPs. Working directly with the families where there is little or minimal change in a young person's health.	X	X
Doctors are trained to find cure for illness, but when MUPs appear frustration can occur when trying different treatments with little or no response in young people's health, then stuckness can present on both sides.	XX	XX
Working with the institutions in which the child and family	X	
Young people and families often experience limited understanding in the early stages of engagement with medical services. By the time paediatricians become involved YP and families may be angry and frustrated by the lack of an answer or access to services who they perceive may hold an answer.	X	X
Access to expertise outside of the medical system may be difficult to access such as in CAMHS with a knowledge of this group, this can be even more difficult for sufferers in the community.	X	X
Need to unpack anger to get any therapeutic movement "everyone wants to get better it is how they get there that the difference and anger can cloud that perspective".	X	
A number of paediatric approaches based on organic assessment can lead to reinforcing the symptoms or on splitting off different parts of the systems.		X
Training experience influences the kind of approach a paediatrician may take.		X
Training experience. Different services specialisms result in different approaches. This affects what kind of service patients receive with medically unexplained symptoms.	X	
Some specialisms demand a wide range of scientific knowledge like endocrinology/neurology which does not allow a lot of time in psycho-social training. This curtails these professionals from appreciation of the complexity of medically unexplained	X	X
Little training experience in months for SHO, SpR and paediatrics. Gaining access to child psychiatry in respect of MUPS medically unexplained symptoms is not always covered.		X
Trainee SpR. Limited teaching on MUPS in child psychiatry.	XX	

The use of the words “medically unexplained” can be limiting and it applies that it could be explained through further medical investigations and rather exclude social factors which in many cases can explain and therefore psychological and social aspects of MUPS is not given sufficient attention.	X	
Lack of training comes to assess problems with MUPS not just academic training but need “experience of being with these families and working with individuals in the system who also may be anxious or frustrated”.	X	
Royal College produced a mind and body training. Paediatricians in training need to attend child mind seminars. Further development in child mind project?	X	
There may be a perception that families and young people are understood in child psychiatry but this is not necessarily always the case.	XX	
Most psychiatrists will focus upon their core business which is schizophrenia or bipolar so it is important to consider the system that you are working with and not make assumptions about this.	X	
Having a close working relationship in hospital between paediatricians and child psychiatrists to deliver a multi-disciplinary training with families is crucial.	X	X
Always been surprised by the chronicity of these cases. Young people severely disabled despite no clear diagnosis with a high level of social educational and family disability.	X	X
Often young people are quiet, and lacking assertion.		X
Some children out of school for more than 2 years, yet this remains unaddressed.	XX	XX
Because other children’s functioning is affected in the long term, we need to tackle the accumulation of disability as well as the medically unexplained symptoms.	X	
It is important in the work not to go fast or too slow and to get the pace of introducing both mind-body ideas right. Continuously reviewing is also important and to reflect on what you are doing session by session.	X	
Difficult issue is to maintain a narrative that focuses on mind, body rather than either/or In hospital close disciplinary working is essential with health, education and social and This less opportunity in community for this inter-disciplinary collaboration including, for example, physios and occupational therapy services,	XX	
Progress should be seen in different ways and include an awareness of the difficulties that young people and their families face.	X	
Assisting young people and families who seek a medical cure to adjust to management of symptoms and personal and family involvement in change.	X	

Progress can often depend upon developing a team around the young person of interest to professionals and individuals who have some experience with difficulties experienced by these young people.		X
The role of paediatricians re. MUPS and with GPs. It can be a failure to undertake this kind of work. It is predominant because of the volume of the work of both paediatricians and GPs.	X	
Problems can arise when they reach 18 years old when college, school and other services drop away and then from a position of some dependency they are faced with transitions to adult care where the levels of support are very different and people will say to them, "we have to empower these young people more to our level. You have to do more for yourself." It appears to be the gulf between the two approaches.	2 subthemes here	
The patients who search for a cure are reinforced by the wider World Wide Web/internet where there are heroic stories of miracle cures. There are pressures on clinicians to know when to stop, the role of doctors is to cure and the need to come up with a label gives the young person and parents something to hang on to.	XX	XXX
Having a label can be important, helping young people and parents to offer expectations. It is important to exclude blame for symptoms in working with families.	X	
"I do not think child psychiatry training adequately covers the issue of medically unexplained symptoms. You need experiences in order to gain confidence in managing the symptoms.	X	X
There is very little understanding in hospital and community specialisms. Perhaps more with GPs.	XX	XX
Paediatricians seen as having an absence/lack of skills in managing than any need for shifting professional worldview outside of medicine in addressing the distress	X	X
Need for different services around the child. Sometimes with mindfulness of the overall problem and the symptoms. Often little attention to history or non-medical factors or family.	X	
Trying to flag up medically unexplained symptoms at an early stage rather than a diagnosis by exclusion.	X	
Tailoring an individual program to suit the child and to helping parents to think differently.	X	
Awareness of the power of the label.	X	
Individual and family distress is an issue. This should be treated equally without need for a defined label".		
Psychiatrist. CBT is the preferred treatment for MUPS yet in many cases when the patient believes the problem resides outside the self that it is physical. This treatment approach can be ineffective.	X	
I believe it is important to try to create the services	XX	X

around the child and young person and their family.		
Introducing the notion of the flexibility of pain not a fixed experience.	X	
Being careful with these patients.	X	
The role of advocacy of a parent is recognised by the paediatrician.	XX	XX
Goes for meaning in response to personal history.	X	
An awareness of patterns in families.	X	
Families need to be included in the work as well. A clear history of transgenerational patterns in terms of illness can be useful.	X	X
Culture and religion important because of the beliefs that all bring with it. Some cultures have different ways of managing uncertainty. It is important to understand these beliefs.	XX	
How do you work as a team with MUPS? Sometimes people have to transcend their own professional roles and beliefs. It is important to have a common understanding between team members and there is a need for a lot of on-going communication between different disciplines in reviewing the child.	X	X
Keeping a prospective on what is happening in family sessions. Also having an outside perspective can be very important (supervision).	X	X
Complexity of medical care. One child can see many different specialisms. Attention needs to be called between transitions between hospital and community.	XX	XXX
Because of the different primary tasks and defined roles can be difficult to work together.	X	
Sometimes joint psychiatric and paediatrics can do a lot to educate others about MUPS. Counting the number of severe cases or educating people publicly, raising the profile of the difficulties for these groups of young people and their families.	XX	X
GPs said they wanted more access by phone and training in preference to joint working. In working in hospital there is some very good examples in relation to joint working on MUPS.	X	X
Positive experience in hospitals, relationships between professionals, would be different in the community if based around the GP or school coordination.	X	
The earlier the young people are referred, the better the prognosis. Often families come to the Paediatric Liaison services two years down the line and it is more difficult to treat.	XX	X
Stigma can be a problem for these families and young people. Preparation by the referrer on what to expect in attending psychotherapy psychology can be very useful.	XX	XX
Psychotherapeutically it is important to reduce the feelings of blame and responsibility for the symptoms.		XX

Families need to be educated about what psycho-social services are available from the outset.		
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Thematic Analysis - Parents Focus Groups

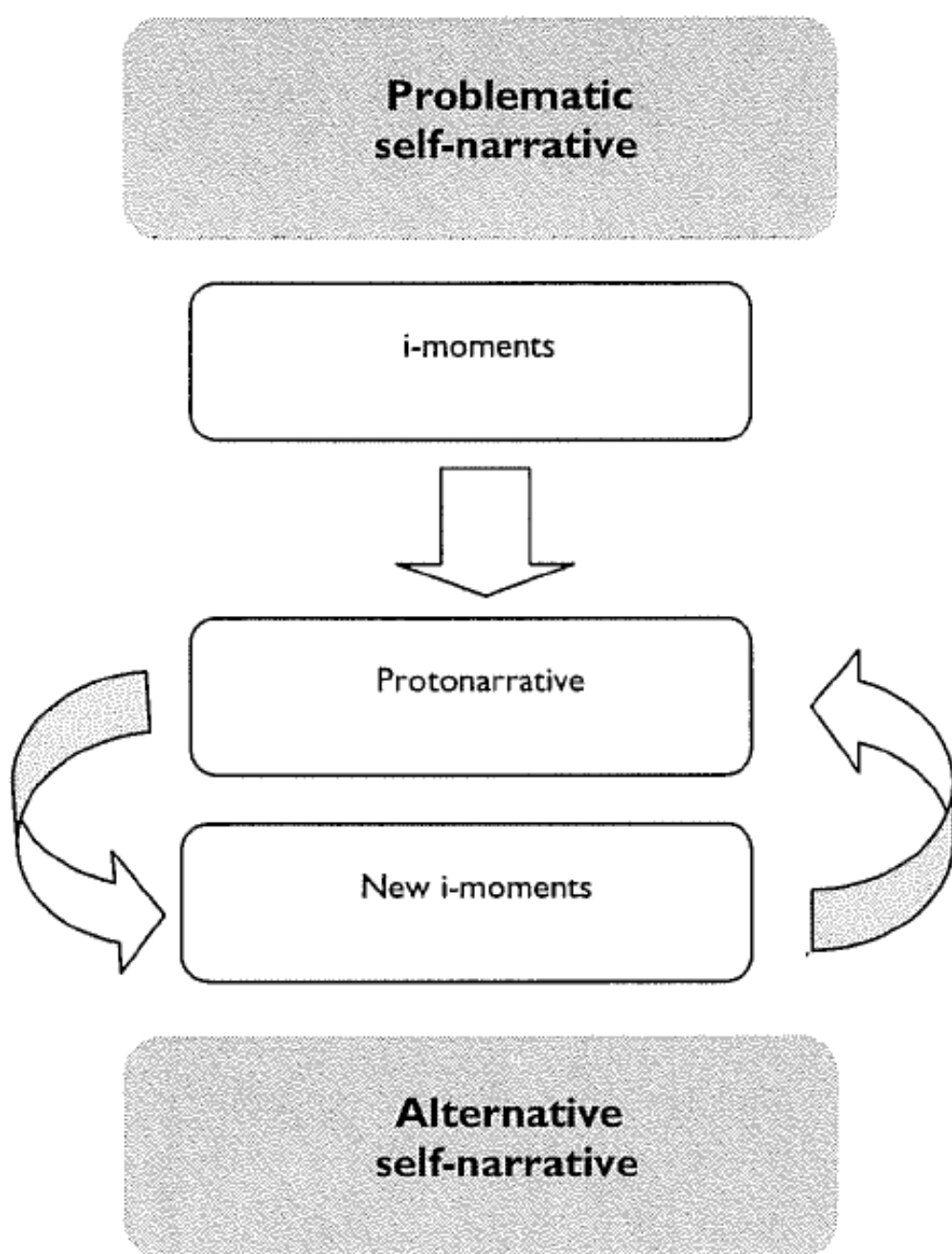
Sub themes	Group 1	Group 2
Schools only concerned with attendance	X	
No facilities young people with symptoms in schools	X	
Doctors do not support parents efforts to enlighten school and attendance officers to Y.P needs		
Teachers not sticking to agreements	XX	
Covert pressure to withdraw the child to remove pressure from school attendance stats.		
Professionals may see the T.P acting/behaving normally in one context and well in another		
Parents give up work-make sacrifices sometimes give up work to care and educate	X	X
“school battle” and “misunderstanding, responsibility always points back towards parents-can you keep a record of toilet use, stomach pain-No we have already done this.	XX	XX
Permission to access facilities inspire giving and repeating information about the Y.P's condition some Teachers continue to disbelief others more understanding	X	
People see the child's behaviour in one context and assume that she/he will be able to reproduce this behaviour in another	X	
Having an advocate in school (teacher or mentor) is valuable	X	
Not believing-not understanding	X	
Responsibility of parents to educate or explain the symptoms at the beginning of illness.		
Pacing the Y.P Activities	X	X
Parental self consciousness about the advocacy role in illuminating others about the child's symptoms	X	X
Questioning teachers and medics authority-knowing more than the professionals	X	X
Play the game of the system if you want to get what you want		X
Parents change become assertive on behalf of your child-demand a Consultant see your child		X
Failure to access information about in different hospitals/medics	X	X
Dissatisfaction with medical Profession opinion feelings of being let down	X	
Striving for further medical investigations sometimes against medical advice	XX	
Appreciation of medics who understand do	X	X

extra tests and discover evidence		
Having to see a number of Drs who only tell you want it isn't despite the ongoing symptoms	X	XX
Y.P-sense of isolation and frustration that there is not a single doctor who can join the YP and family on the journey to discover what is behind the illness	XX	
Keeping track of all medical consultations as it may not be recorded in notes	XX	
Frustration with doctors because they cannot see what we can see. Searching for a physician who will tell us what it is.	X X	X
Lack of confidence in medical profession. loss of respect for authority		
Appreciation of Dr. who showed interest and continues to pursue answers		
previous experience of chronic illness (father) made it easier to assimilate when M got ill		X
Disbelief-non legitimatisation of parental and young persons descriptions of pain "it was really hard to get a medical professional to trust us"		X
Message of disbelief by medics and other professionals undermines parental authority and intimate knowledge of their child.	X	
If medics cannot discover organic cause to ready to assume that it is psychological		X
Dr. disbelieves you it goes on file" difficult from the on to change their mindset about the symptoms. Biggest issue not being believed as a family mother notices "fussy parent" is on his file at Drs.	XX	X
Without confirmation of illness you question yourself, you question your child, questioning medical expertise and authority.		X
Disbelief in institutions if something cannot be discovered then it doesn't exist	X	X
Early diagnosis would have saved a lot of emotional physical suffering one simple test.	X	
Importance of diagnosis. giving the child hope-making the child stronger	X	
Gender - Boys don't like fussiness, don't like to show weakness		X
Views of YP's temperament and self and responses to medics and treatment	X	
How sickness experience can intensify demands and need to control	X	
Cannot be seen-medical disbelief can make you have doubts-medications working is confirmation-often isolated "have to counsel yourself". Protecting other family members from	XX	X

your grief. Guilty if off load onto others.		
Protection and Conflict with Grandparents over how to get YP better. parent feeling blamed.		X
Household were young person lives with two generations who have illness and disability		X
I think I failed her-I still think that		X
Rebuilding relationship with child has low emotional reserves		X
Tensions when couples don't agree on the symptoms.		X
Toll on personal health due to unending stressors pressures can be relentless	X	
Family and child increasingly isolated from extended family, friends etc	X	XX
Increasing dependency and regression of the child. Phoning at work "when are you coming home, what are you buying for me?"		X
Siblings can be supportive, but at the same time expectations upon the are greater for practical and sometimes emotional support to the parents and ill child		X
Mother and child increased closeness	X	X
Difficulty discerning how much behaviour is down to the condition and how much is teenage behaviour	XX	
A 90 year old grandmother lives with family. They are used to making allowances as chronic illness in the family. Father has MS. Never really went through teenage things.		X
Perceptions of other families - See everybody else around you having a life and then envy people for just doing normal things.	X	X
Changing Lifestyles - She used to take sports football-lost interest in this-you change your life completely-Its completely turned upside down	X	XX
Child psychologist couldn't see a role for himself. couldn't see anything wrong with her-"nobody listened well they thought I was a paranoid mother"	X	
Impact on relationships in the family - Arguments and conflict can occur when couples disagree about the nature of symptoms	XX	
Parental challenges - Child with ME "burns the candle at both ends" lack of self regulation in child young person to measure energy"		X
Symptoms and the Search for Diagnosis:		
Origins, virus buga (innocuous beginnings) and nature of symptoms, headaches, fatigue, stomach pain, sickness	X	

Diagnosis by discounting other things, rather than positive diagnosis,	X	
Request for invasive treatments	X	
Multiple tests with negative results from specialists returning to G.P who put it back to you" always getting knocked back to stage one		XX
Little reassurance from medics insufficient investigations, there are things that medics have missed or even simple tests that have not yet been applied		XX
No continuity or communication between doctors over different consultations	X	

Gonçalves, M., & Ribiero, A., P., (2012) Therapeutic Change, Innovative Moments and the Reconceptualisation of the Self: A Dialogical Account.



Different levels of narrative development

Appendix 4

Transcription Notation:

(.) A full stop inside brackets denotes a micro pause, a notable pause but of no significant length.

(0.2) A number inside brackets denotes a timed pause. This is a pause long enough to time and subsequently show in transcription.

[] Square brackets denote a point where overlapping speech occurs.

> < Arrows surrounding talk like these show that the pace of the speech has quickened

< > Arrows in this direction show that the pace of the speech has slowed down

() Where there is space between brackets denotes that the words spoken here were too unclear to transcribe

(()) Where double brackets appear with a description inserted denotes some contextual information where no symbol of representation was available.

Under When a word or part of a word is underlines it denotes a raise in volume or emphasis

↑ When an upward arrow appears it means there is a rise in intonation

↓ When a downward arrow appears it means there is a drop in intonation

→ An arrow like this denotes a particular sentence of interest to the analyst

CAPITALS where capital letters appear it denotes that something was said loudly or even shouted

Hum(h)our When a bracketed 'h' appears it means that there was laughter within the talk

= The equal sign represents latched speech, a continuation of talk

:: Colons appear to represent elongated speech, a stretched sound

Jefferson, G. (2004), Glossary of Transcript Symbols with an Introduction. in G. H. Lerner (Ed). Conversation Analysis: Studies from the First Generation, (pp: 13-31), Amsterdam: John Benjamins.

Appendix 5

Innovative Moments

The 'IM' can be described as a meta-moment in the nature of the I-position. In the context of therapeutic relationship there are four functions of the IM with a focus upon the potential for change 1) Providing a narrative structure for change; 2) Bridging the past and present self-narratives; 3) Facilitating the progressive identification with the new self narrative; and 4) Surpassing the ambivalence often involved in the change process (p.81).

I thought it would be useful to adapt this model of clinical analysis of the therapeutic dialogue to the research analysis of participant's accounts. I considered the model would be useful to the analytic process in terms of unpacking the ruminations involved in ambivalence and the naturally occurring processes in any movement from a problem self narrative to possibilities for change within all participants accounts.

Appendix 6

It was August and Andrea was at school and she wasn't well, and I think the next day she had diarrhoea about two days, and the sickness started – violently sick. I took her to the doctors. Doctor said, "That's gastroenteritis" and then I think after about six or seven weeks off school we were referred to a private paediatrician who was trying to help us and then he had a stroke (.) Then referred to irritable bowel and just kept throwing tablets at her, and they were making symptoms worse. [Martin: And we saw a different Consultant] (.) And we saw a different Consultant (.) and she had constant wind – really bad wind, and also constant pain in her side where she couldn't move. And she'd just be let down (tearful) used to have to go to work and leave (tearful) 'cos they say she'd got to get on with it, she got to see you go to work. And I couldn't concentrate at work and the phone would go and I don't know how I survived that. Eventually I wanted her to have some tests; I wanted her to have the camera down (1) and Dr. Z wouldn't do it he said it was too invasive, but I thought her illness was invasive (.) So eventually we found a wonderful Dr. C at Sheffield and he's a Paediatric Gastroenterologist. We had to go through him privately and he did all the tests that Leicester wouldn't do. He took her in for a whole day and he took biopsies from everywhere and he found one tiny little result and he found that er, her sugar level and her refined sugar level was low which indicated that something was feeding off it (.) So he treated her for that which was several lots of antibiotics which was a strong dose, so we had to go to see Dr. G at Sheffield just to get these prescriptions and think we had five courses and it was over a week wasn't it? [Martin: Yeah] (1) She was having 16 tab, er, 20 tablets a day and syrup and it bring out in a ((gestures with hands over neck)) well she wasn't allowed to get a rash was she? She had to suffer all this stomach ache again. He said to her her skin would itch. He said you've got to take every symptom that these give to you because it is cleaning it out (.) so we had five lots of that (1) because Dr. Z did give her antibiotics in the end (Appendix 3).

Martin: Do you want me to go through describing drug stated work for a few weeks try.

Carol (contd.): I wanted it and she picked up didn't she and that going back a bit Dr. Z did give her antibiotics and she picked up a bit by telling Dr. C that he knew give her the indication that there was something there [**Martin:** It was after a breath test] it was after a breath test that she'd had yeah. Um, so Dr. C treated her for the um bacteria overgrowth, but she still wasn't right. Well then you could see the wind going and other symptoms, but it still wasn't right and I was wondering about ME because I used to go – for all these months I used to go on the internet and find out could it be this, could it be bacteria and then you try and you actually go mad. And my doctor said er, she phoned me and said she'd heard a radio programme on ME 'cos she never realised that ME could show itself as irritable bowel or >> other symptoms like that,<< and I spoke to Dr. C and he said he thought it was ME. So that's when he diagnosed her with ME and couldn't actually find a Consultant at the time so he actually started her on medication (1). And then Dr. N found Sally (CFS/ME) coordinator and now I mean Andrea is struggling but she is at school now, and she's at school now and she's actually catching up on her coursework. Now she does get stressed and tired but if you think this time last year >> she couldn't even stand up<<. But she gets side pain now and she gets tired: she's on medication but its having that diagnosis [Kathleen ((nodding)) yeah yes] No, it's right you get that diagnosis so we knew what's wrong now and then with the medication and the instructions you're given you see improvement. So you know, that's what's wrong with her although you can't (.) see it.